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**CONSIDERING ALTERNATIVES TO THE PREDOMINANT MODEL OF  
VOLUNTARY COUNSELLING AND TESTING PRACTICED IN SOUTH AFRICA**

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**COMPULSORY DECLARATION**

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: ..... Date: .....

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## ABSTRACT

Testing is widely acknowledged to be a useful and necessary secondary tool of Human Immunodeficiency Virus (HIV) prevention. It is the method by which to identify people who are living with the virus, so that their behaviour may be modified and medical condition treated in order to prevent further infection. Unfortunately, many persons in South Africa (SA) remain undiagnosed and therefore unaware of their HIV-positive status.

This thesis explores why it is necessary to test for HIV in SA, where the incidence of the virus remains the highest in the world. Voluntary Counselling and Testing (VCT) or the 'opt-in' approach has been adopted as the norm or 'sine qua non'. The efficacy of this method will be interrogated and shortcomings identified. The most notable is that few people in SA undergo an HIV test in order to learn their status. When they do, it is often late in the progression of opportunistic infections, requiring hospitalisation that increases pressure on an already over-stretched healthcare system. Reasons for the poor uptake of VCT are explained, including pervasive stigma and deficiencies in leadership of SA's HIV and AIDS response.

The expansion of testing is a proposed response to the challenge of persons remaining undiagnosed, and includes the acceleration of 'opt-out' or routine HIV testing (RHT) among SA's high prevalence population. This model offers an HIV test routinely to persons attending government healthcare settings with an illness or for a routine check-up. Although the provider initiates the test, consent is necessary in order to proceed and there is an option to decline.

While the key focus of this thesis is routine HIV testing, other approaches are explored in brief, including mandatory testing, mobile clinics and wellness screening. The thesis argues that if SA is to achieve the HIV and AIDS and STI National Strategic Plan (NSP) target of increasing the number of adults who have ever had a test to 70 percent by 2011, new approaches to testing, and especially opt-out, will need to be explored and more widely adopted.

**Key words:** HIV/AIDS; Voluntary Counselling and Testing (VCT); Routine HIV Testing (RHT); Routinely Recommended Testing (RRT); Opt-out Testing; Provider-Initiated Testing and Counselling (PITC).

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## **GLOSSARY OF TERMS**

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ARK</b>	Absolute Return for Kids
<b>ART</b>	Antiretroviral Therapy
<b>ARV</b>	Antiretroviral
<b>AZT</b>	Azidothymidine (a type of antiretroviral drug)
<b>BCG</b>	Bacillus Calmette-Guérin (tuberculosis vaccine)
<b>BONELA</b>	Botswana Network on Ethics, Law and HIV/AIDS
<b>CDC</b>	Centers for Disease Control and Prevention (USA)
<b>DBSA</b>	The Development Bank of South Africa
<b>DoH</b>	Department of Health
<b>DTHF</b>	Desmond Tutu HIV Foundation
<b>EIA</b>	Enzyme Immunoassay
<b>HAART</b>	Highly Active Anti-Retroviral Therapy
<b>HIV</b>	Human Immunodeficiency Virus
<b>HIVCTR</b>	HIV Counselling, Testing and Referral
<b>HSRC</b>	Human Sciences Research Council
<b>HSV</b>	Herpes Simplex Virus
<b>IIDMM</b>	Institute of Infectious Diseases and Molecular Medicine
<b>KBP</b>	Knowledge, Behaviour and Practice
<b>MCC</b>	Medicines Control Council
<b>MMWR</b>	Morbidity & Mortality Weekly Report (of the CDC)
<b>MSF</b>	Médecins Sans Frontières
<b>MSM</b>	Men who have Sex with Men
<b>MTCT</b>	Mother-To-Child Transmission
<b>MRC</b>	Medical Research Council
<b>NACA</b>	National AIDS Coordinating Agency (Botswana)
<b>NSP</b>	National Strategic Plan
<b>OI</b>	Opportunistic Infection
<b>PCP</b>	Pneumocystis Carinii Pneumonia
<b>PHC</b>	Primary Health Care
<b>PITC</b>	Provider-Initiated Testing and Counselling
<b>PLWHA</b>	People Living With HIV/AIDS

<b>PMTCT</b>	Prevention of Mother-To-Child Transmission
<b>PrEP</b>	Pre-Exposure Prophylaxis
<b>PSA</b>	Prostate Specific Antigen
<b>RHT</b>	Routine HIV Testing
<b>RRT</b>	Routinely Recommended Testing
<b>RTC</b>	Routine Testing and Counselling
<b>SA</b>	South Africa
<b>STI</b>	Sexually Transmitted Infection
<b>SWS</b>	Student Wellness Service (at UCT)
<b>TAC</b>	Treatment Action Campaign
<b>TB</b>	Tuberculosis (Pulmonary)
<b>UCT</b>	University of Cape Town
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNDESA</b>	United Nations Department of Economic and Social Affairs
<b>VCT</b>	Voluntary Counselling and Testing
<b>WHO</b>	World Health Organization



## INTRODUCTION

Over 5.2 million people are living with HIV in South Africa (SA) (Shisana et al., 2009). The UNAIDS (2007) notes the “localized reduction in prevalence in specific countries” has not been observed in SA. HIV prevalence among females aged 25 to 29 persists at a high level of 33 percent, and prevalence levels have risen among adults aged 15 to 49 between 2002 and 2008 in most provinces, the highest of which is KwaZulu-Natal at 10.1 percent (Shisana et al., 2009). Otherwise, a levelling out of prevalence can be attributed partly to the continual deaths from AIDS that disguise the real rate of new infections (Butler, 2009).

According to Dr Venter (2008), president of the Southern African HIV Clinicians Society, despite the fact that the prevention of mother-to-child transmission (MTCT) is being promoted, there are 70,000 paediatric infections per annum in SA. Presently, fewer than 80 percent of pregnant women are tested for HIV, suggesting an urgency to accelerate the promotion of prevention of mother-to-child transmission (PMTCT) (Day et al., 2009). At least there has been a decline in prevalence among children, attributed mostly to the success of programmes in the Western Cape to prevent MTCT (Shisana et al., 2009).

Additionally, in spite of an antiretroviral (ARV) roll-out since 2002, people continue to die of AIDS; 3.7 million since 2003, with almost 722,000 in 2007 alone (Momberg, 2008). The Treatment Action Campaign (TAC), an NGO advocating for the rights of people living with HIV/AIDS (PLWHA), estimates that whilst there are approximately 700,000 people taking ARVs in SA’s public health sector, at least double this number need treatment. Additionally, five people become infected with HIV for every two who start taking ARVs (Beresford, 2008). UNAIDS (2007) blames infections with HIV and deaths from AIDS “mostly” on “inadequate access to HIV prevention and treatment services”.

The above statistics clearly demonstrate prevention efforts are failing SA, a country where the HIV epidemic is bound up with contextual complexities: extreme inequalities of wealth and opportunity, a large rural populace distanced from better resourced urban centres and an under-resourced and transforming health service guided by the primary health care (PHC) approach. Whiteside (2008) states “The one critical thing is prevention. It’s common sense. If we can prevent infection, we don’t have to treat it. We have failed hopelessly”. The epidemic continues to thrive in SA, despite the implementation of prevention efforts for over 20 years.

In view of the above, perhaps it is time to take a fresh look at prevention efforts. Vaccines are a long way off and a microbicide has to date proved elusive (Nelson, 2007; Shelton, 2007; Microbicides Development Programme, 2009). The use of diaphragms and lubricant gel by women has not proved effective against the virus (Padian et al., 2007), pre-exposure prevention or PrEP utilising ARVs as a prevention measure is still in the trial phase (Hillier, 2008) and suppression of Herpes Simplex Virus 2 (HSV-2), a sexually transmitted infection (STI), has not worked (Watson-Jones et al., 2008).

Male circumcision has been found to reduce the possibility of transmission of HIV from women to men by up to 60 percent (Auvert et al., 2005; Williams et al., 2006; Halperin & Epstein, 2007; Weiss et al., 2008; Klauser et al., 2008), but there is no national policy on circumcision to date (Shelton, 2007). Also, Sithole et al. (2009) indicate there is ambiguity in the term 'circumcision', since Zulus only remove the tissue under the penis glans and not the foreskin ('ukugweda' or partial circumcision). They therefore caution against wide promotion until more evidence comes to light of effectiveness and acceptability, and indicate public health messages have to be adapted to suit different cultural contexts.

Condoms have been widely distributed and extensively promoted through social marketing campaigns in SA by government and non-government actors alike, with a 14-fold increase in distribution between 1997 and 2004, yet HIV incidence has failed to significantly decline. This could be attributed in part to the failure of 90 percent of people to use condoms at every sexual encounter (Venter, 2008; Halperin & Epstein, 2007; Shelton, 2007). On a more positive note, there was an increase from 57 percent in 2002 to 87 percent in 2008 of men aged 15 to 24 using condoms and from 46 to 73 percent among the same age group of women. Condom use doubled for men aged 25 to 49 and tripled among the same age group of women (Shisana et al., 2009). The essential promotion of condoms must be combined with other prevention tools.

Messaging (public service announcements and techniques of social marketing) has an important part to play in the HIV prevention effort. This includes messages that tackle structural causes or 'drivers', such as: stigmatising behaviours (Chesney & Smith, 1999); concurrent sexual partnerships (Epstein, 2007), which have increased by nearly 10 percent among males aged 15 to 49 between 2002 and 2008 (Shisana et al., 2009); and gender

inequalities, highlighted in a Medical Research Council (MRC) Policy Brief on rape and HIV by Jewkes et al. (2009).

More messaging is needed to reach high-risk groups, including men who have sex with men (MSM), recreational drug users, heavy drinkers, women aged 20 to 34 and men aged 25 to 49. Messaging is at least reaching the younger population of SA: 90 percent of young people report having heard at least one programme, compared with only 38 percent of persons over 50 years. However, despite this messaging, HIV prevention knowledge has declined at national level among the 15 to 49 year age group (Shisana et al., 2009).

Then there is the secondary prevention tool of HIV testing, which will be the central focus of this thesis. It is a screening process that determines the HIV status of a person. Such testing was introduced in the 1980s as Voluntary Counselling and Testing (VCT), where the onus is on the individual to test. Whilst other tests, like those for diabetes or cancer, are offered and undertaken unless the client expressly refuses, HIV has been afforded a special status, with an emphasis on the ‘three Cs’ of consent, counselling and confidentiality, argued in terms of the protection of human rights. This came about largely because of early associations between the epidemic and the stigmatised community of gay men on the west coast of the USA, the mainly sexual mode of transmission and the link between incurable HIV, disease and death (Herek & Glunt, 1988; St. Lawrence et al., 1990). The stigma of the disease extended to the testing site, affecting the willingness of persons to go for a test (Myers et al., 1993; Stall et al., 1996; Chesney & Smith, 1999).

‘AIDS exceptionalism’ was born out of the lack of treatment availability, the perceived inability of healthcare facilities to protect confidentiality and concerns that MSM would be further discriminated against (Bayer & Fairchild, 2006; Jaffe, 2009). The thesis will argue that there is no longer any need for exceptionalisation of the testing process and that there may be more effective ways in which to test persons for HIV than through VCT.

To what extent is testing in itself a useful and necessary tool of HIV prevention? There are those who argue that, given the stigmatisation of the disease, letting people know they are positive years before they are at risk of becoming sick may be an act of cruelty. There are also concerns that rapid testing kits can produce false positive results (where a person who tests HIV-positive is actually HIV-negative). This false knowledge can be harrowing for a

person. However, the rapid test in common use in SA has a high sensitivity (accuracy in detecting HIV-positivity) and specificity (accuracy in detecting HIV-negativity), with only a tiny percent of false positives.

*Chapter One* of this thesis highlights the overwhelming individual and societal benefits of testing, which far outweigh any concerns. It will seek to demonstrate that testing is an important aspect of prevention and care and hence an appropriate response to the HIV epidemic in a situation of limited healthcare resources.

When people are ignorant of their status, others may be unknowingly infected, particularly as symptoms are not necessarily in evidence. Knowledge of status affords persons the opportunity to reduce onward transmission. There is strong evidence (Weinhardt et al., 1999; Crepaz & Marks, 2002; Marks et al., 2005; Bartlett & Mayer, 2006; Delpierre et al., 2007) that people who test positive change their behaviour to engage in safer sex. However, evidence is inconclusive that people testing HIV-negative adopt more responsible sexual behaviours (Higgins et al., 1991; Fleming et al., 2000). Paradoxically, viewing HIV as a manageable medical condition may make some people less careful regarding their sexual behaviour. Thus as a prevention tool, testing has great value, but limitations must be recognised.

Notwithstanding, there are considerable benefits associated with testing, principally of 'enabling' treatment for HIV – knowledge of one's HIV-positive status is essential to be able to receive treatment and to live healthier for longer. Initiation of ARVs means less rapid progression to the onset of opportunistic infections (OIs) and a reduction in the exorbitant cost of hospital treatment. Additionally, knowledge of a woman's HIV-positive status will enable the appropriate action to prevent transmission to a child.

*Chapter Two* interrogates VCT and questions its efficacy. It argues that a method accessible to only a few cannot identify sufficient HIV-positive persons. When HIV is identified, it is often too late in the infection stage for effective treatment, which makes this method outmoded.

The HIV and AIDS and STI Strategic Plan for South Africa (NSP) 2007-2011 aims to increase by 60 percent by 2010 and 70 percent by 2011 the number of adults who have ever had an HIV test, and the number of adults testing in a year by 22 percent for 2010 and 25 percent for 2011. If this target is to be achieved, new approaches to testing will need to be

explored and more widely adopted. *Chapter Three* discusses the feasibility of expanding the introduction of opt-out or routine HIV testing (RHT), rather than continuing to focus on the opt-in or VCT approach. Opt-out testing is an offer of a test, given to a person attending a government health facility with an illness or for a routine health check (Cockcroft et al., 2007). This is an approach that has been widely adopted in Botswana, which is analysed as a case study. It is acknowledged by the author that Botswana is a country with a different history and economic climate to SA, and a much smaller population. However, the experience of one of SA's high prevalence neighbours remains relevant and its lessons are important. The value of the opt-out approach is evaluated in terms of uptake, early detection of HIV and general awareness of one's HIV-positive status.

*Chapter Four – Research Methodology* – explains the reasoning behind the utilisation of a literature review and an interview approach. The thesis is based on in-depth interviews with key informants in the epidemic, who have long experience of its challenges in the Western Cape. They are Physician Dr Linda-Gail Bekker, Constitutional Court Justice Edwin Cameron, Economist Dr Susan Cleary, Public Health Specialist Dr David Coetzee, Epidemiologist Dr Rodney Ehrlich, HIV Clinician Dr Ashraf Grimwood, Pharmacologist Gary Maartens, and University of Cape Town (UCT) Human Resource specialists, Margie Tainton and Ashley Taylor.

All informants were selected for their academic excellence, skills of interpretation, peer-reviewed research output, and wide knowledge concerning health economics, epidemiology or other field of expertise – and the esteem in which they are held. In selecting persons for interview, I did not succeed in identifying any active opponents to the pursuit of other forms of testing for HIV. This is not to suggest they do not exist. Chapter Four provides more comprehensive information on each respondent, which will serve to elucidate why they were selected for interview.

The *Chapter Five* discussion seeks to investigate whether there is a need for a change in testing methodology, as the landscape has altered inexorably over more than 27 years of an HIV response. As Supreme Court Judge and AIDS activist Edwin Cameron (2005) states, “Where treatment is available, signs increasingly suggest that the exceptionalisation of HIV infection in the healthcare setting may be impeding its effective management”. With the advent of antiretroviral therapy (ART) in SA in 2006, and its increasing availability, HIV is

progressively being regarded like any other chronic, manageable condition, and no longer a death sentence.

Dr Linda-Gail Bekker (2008), Principal Investigator at the Desmond Tutu HIV Foundation (DTHF), argues testing needs to be demystified. There is a need “to call it what it is... it’s a test. Like you get your blood pressure tested or your glucose tested, you need to get tested”. ‘Normalising’ testing will reduce its association with stigma and discrimination. The chapter enquires whether RHT, reviewed as effectively implemented in Botswana, could be introduced more widely in SA.

The *Conclusion* draws together the challenges, emphasising the need to adopt a number of different approaches to screening, in a leadership-driven, concerted effort, so that SA is able to provide an appropriate and effective response to testing for HIV and achieve anything close to the ambitions targets for the NSP. *Recommendations* are given for the way forward.

## **CHAPTER ONE: THE IMPORTANCE OF TESTING FOR HIV IN SA**

### ***Introduction***

The prevailing view among international and SA HIV and AIDS experts is that testing is critically important both for prevention and effective treatment. They argue that if an individual knows her/his HIV status s/he is more likely to adopt safer sex behaviours; more likely to start leading a healthy life-style if s/he is not doing so already; and will be able to start treatment as soon as it is needed, rather than when s/he is already very ill – the case with many people. Late treatment increases the costs of treatment exponentially because the person often needs intensive care in hospital for a long period; it means the person is infectious longer than need be and it leads to many unnecessary and costly deaths among those for whom late treatment fails.

There are, however, important resource implications of earlier testing, coupled with significant social barriers. If testing is encouraged, it should ideally be accompanied by a CD4 test to determine the level of infection and monitor its progress. This is not possible in many testing settings. Earlier testing also implies support for those living with a positive diagnosis, including psychological support. There are two recognised periods of major depression linked to a positive diagnosis: following diagnosis and when treatment is recommended. However, psychological services simply are not available for most of SA's population. The question of stigma is also critical. While this may not be as pronounced as it was in the early years of the epidemic, people still fear it. It is one reason why some people would rather be ignorant of their status. This chapter will discuss these issues.

### ***Psychological impact***

Learning one's HIV-positive status is a life-changing experience, which can be traumatic. It means adopting new behaviours and starting a lifetime regimen of drugs. Furthermore, fear of social ostracism and internal self-stigmatisation make the positive diagnosis an ongoing source of anguish for many. Grace Sedio, a public figure living with HIV in Botswana, suggests difficulties in accepting the reality of an HIV-positive status can adversely affect treatment adherence.

Ehrlich (2007) describes anecdotal evidence that suggests unrelated ill-health symptoms and anxieties are likely to develop and Grimwood (2007) highlights the issues of fear and denialism, and the complexities around stigma and trying to manage a grief reaction. Gary Maartens (2007), one of Cape Town's most experienced HIV/AIDS physicians, suggests there are particular situations, including heavy depression or suicidal risk, when a health practitioner should defer sharing news of an HIV-positive test result.

### ***Lack of symptoms***

Healthcare providers in SA are increasingly trained to be aware of possible symptoms of acute HIV infection, including dry coughs, recurring fever and night sweats, headaches, unexplained fatigue, nausea, diarrhoea, enlarged lymph nodes and rapid weight loss. Rodney Ehrlich (2007) argues each generation of trainee doctors coming through will know more and be better geared to diagnose HIV infection. He says if someone presents with a chronic cough, "the first three things we look for are tuberculosis, tuberculosis and tuberculosis".

However, a prolonged asymptomatic period after infection means people living with HIV may have no symptoms for ten years or more post-infection. Acute HIV infection is difficult to diagnose, as flu-like symptoms (listed above) are easily mistaken for another viral infection, often disappearing after a week to a month. In research by Pincus et al. (2003), patients with acute HIV infection could not be "reliably distinguished" from HIV-negative patients through identification of symptoms or physical findings.

Waiting for symptoms is ill-advised as they typically occur late, when the viral load is high, the CD4 cell count low and OIs occur. This is particularly pertinent to the testing of pregnant women, when there is another life at stake (Maartens, 2007). Coetzee (2007), a public health expert, describes people coming to his clinics with a CD4 count of well below 200 cells/mm<sup>3</sup> who have never had a single symptom – they only learn their status because they are pregnant. Likewise, people who present with an STI, but are otherwise well, learn they are HIV-positive only because they are tested. Ultimately, the only way to know the status of individuals (and determine the prevalence and incidence of HIV in a population) is to test for HIV (Henn et al., 2006).



### ***Reduced risk of transmission***

So, testing is necessary in order to confirm a person's HIV status. However, does evidence support the assertion that testing results in a reduction in viral transmission?

Research is inconclusive (and opinion is divided) regarding whether a negative test result encourages sexual behaviour change (Shelton, 2007). Evidence (anecdotal and otherwise) suggests short term behaviour modification at most. Higgins et al. (1991) reviewed 50 research studies in published abstracts, journal articles and presentations that analysed the effects of HIV testing and counselling on risk behaviours. They focused on homosexual men, intravenous drug users, pregnant women and other heterosexuals. They found scant evidence to suggest people who test negative would practice safer sex. Indeed the studies suggested high-risk behaviours may be adopted if people perceive treatment to be effective and therefore worry less about becoming HIV-positive. Fleming et al. (2000) point to anecdotal evidence amongst gay men supporting this theory.

Holbrooke and Furman (2004) do suggest if people test negative there is an incentive for them to start practicing safer sex. Ehrlich (2007) also speculates a negative test result may make a difference: "I've been so worried, I've been paralysed, and now that I know I'm negative it gives me a bit of control back". There is some evidence to support these remarks. Surveying clients at a Milwaukee Health Department STD clinic in the USA, DiFranceisco et al. (2005) used regression analysis to show that people engaged in safer sex directly after testing for HIV. They identified a "brief surge" in condom use amongst women and men recently counselled and tested for HIV, whether HIV-positive *or* negative, which lasted a few months. Bekker (2008) suggests more research is needed to ascertain whether sexual behaviour changes when people test HIV-negative, asserting that her own prevention trials have seen behaviour modification.

Research evidence is much stronger in support of the theory that knowledge of one's HIV-positive status reduces the likelihood of viral transmission. Weinhardt et al. (1999) report increased condom use and a reduction in unprotected sex among HIV-positive participants and HIV-serodiscordant couples after counselling and testing. They conclude testing and counselling is therefore an effective means of secondary prevention when people test HIV-positive. A meta-analysis conducted by Marks et al. (2005) also shows people who know they

are infected with HIV reduce their practice of high-risk sex by about half. Rates of STI transmission are also much reduced. However, this study did not analyse behaviour change over time and unprotected sexual behaviour may be under-reported. Bartlett (Bartlett & Mayer, 2006) argues that those who test positive make an effort to prevent infecting others and manage to reduce transmission even more substantially (four-fold from nine percent to two percent), while Crepaz and Marks (2002) assert that widespread HIV testing brings a reduction or elimination of transmission behaviours of between 50 and 66 percent.

Finally, the South African Department of Health (2007) draws on several studies when it asserts that there is an increase in prevention behaviours and risk reduction strategies among people who know their HIV-positive status.

### ***Pre- and post ARV availability***

Despite a dramatic increase in the provision of ARVs in sub-Saharan Africa (UNAIDS, 2006), and an expanding roll-out in SA, many people are still without access. The TAC (2009) notes that “at least double the current number of people who are on ARVs need treatment urgently to survive”. Even the Health Minister Aaron Motsoaledi admits that the targets of the NSP are over ambitious in a country with funding shortfalls, a shortage of health professionals and an overburdened health sector – only 700,000 people are receiving ARVs, a half of the NSP target (PlusNews, 2009). Testing does bring with it the expectation of treatment and Alcorn & Smart (2006) argue that the benefit of learning one’s status is questionable without it. It is therefore pertinent to ask whether testing should be promoted when ARVs are not universally available.

It is important for services to be able to provide prevention support for people testing negative and for people to be referred for care who are HIV-positive – even if they are not yet ready for highly active antiretroviral therapy (HAART) (HIV & AIDS Treatment in Practice, 2007). A healthcare provider may assist a patient by providing valuable information and encouraging responsible life choices, such as practicing safe sex, avoiding re-infection and transmitting the virus, eating properly, quitting smoking and managing stress (Coetzee, 2007).

Additionally, non-ARV medical interventions are available for PLWHA, in order to prolong life (De Cock, 2006). In resource-rich Western countries, treatment has brought a drastic

reduction in the frequency of *Pneumocystis Carinii* Pneumonia (PCP), an OI related to HIV (Clumeck, 1995). Farham (2007) confirms that a person with PCP can receive regular prophylaxis of co-trimoxazole or Bactrim® or pentamidine, all of which have a treatment success rate of 70 to 80 percent. Using a model-based approach, Walensky et al. (2006) found that “compared with survival associated with untreated HIV disease, per-person survival increased 0.26 years (3.1 months) with PCP prophylaxis alone”. There are also a number of prophylaxes available for the treatment of, for example, candidiasis or thrush and toxoplasma encephalitis (Farham, 2007).

Co-trimoxazole or *Bactrim*® has been used in clinical settings in SA for about 10 years to treat OIs (Maartens, 2007; Grimwood, 2007; Ehrlich, 2007). It is described by Maartens (2007) as “a very good and cheap prophylactic antibiotic that reduces death rate by about 45 percent for advanced patients”. Stating that it is not worth testing at public health level for something that cannot be treated, he asserts that HIV does *not* fall into this category, as good interventions are available that decrease morbidity and mortality, even with severe immune impairment.

A number of commentators describe the important shift in perception from AIDS as a death sentence to management of HIV as a chronic condition, with the advent of ARVs. Mark Heywood (2005) of the AIDS Law Project describes a shift from “an invariably fatal” disease and Cameron (2006a; 2007) asserts that even in resource-poor settings, the prognosis is “excellent” once a person is on a constant and appropriate regimen. Dr Banu Khan, the National Coordinator of the National AIDS Coordinating Agency (NACA) in Botswana, argues that it is necessary to approach HIV differently from the early years of HIV incidence, since free treatment is now available (BONELA, 2003).

WHO’s 3 by 5 initiative and declaration to work towards universal access to ARVs (Heywood, 2005), the commitment to treatment roll-out by the Global Fund and PEPFAR, and Millennium Development Goal commitments (UNDESA, 2007) speak to making ARVs available to all. For this to happen, and to ensure people do not remain undiagnosed and die of AIDS, testing for HIV needs to be considerably expanded (Hamill et al., 2007). WHO/UNAIDS (2007) describe a “critical opportunity” to expand prevention efforts.

From the public health and clinical perspective it is critical to diagnose HIV early, before the onset of OIs (De Cock & Johnson, 1998). Later identification may result in irreversible immunological damage and death (Sanders et al., 2005; Delpierre et al., 2007). As ARVs are increasingly available in resource-poor settings, Bendavid et al. (2008) highlight the value of CD4 cell count monitoring and early treatment in terms of cost-saving and health benefits through preventing hospitalization and prolonging life. Grimwood (2007) and Bekker (2008) believe in the importance of getting one's CD4 cell count taken immediately after testing positive for HIV, in order to learn whether it is necessary to start on ARVs. There is also an opportunity for counselling provision, and for ongoing discussions and questions.

The considerable value of ARV provision after testing for HIV is recognised by a number of commentators in terms of life-years gained. Bartlett (Bartlett & Mayer, 2006) argues that it would be difficult to match HIV in terms of treatment dividends. Walensky et al. (2006) record the 3 million life years being saved since the advent of treatment in 1989. Venter (2007) asserts that 30 life years can be earned if a person starts in good time on an ARV regimen. Sanders et al. (2005) estimate, with use of a model, the increase in life years of 1.52 when HIV is identified and treated early (HAART was initiated at CD4 count of 350 cells/mm<sup>3</sup> as opposed to the average of CD4 count of 175 cells/mm<sup>3</sup>).

### ***Administering treatment***

In resource-constrained SA the debate is ongoing about when a person should begin to take ARVs. Reasons given for delaying treatment include “the toxicity and inconvenience of drugs, fear of rapid resistance accumulation, and likelihood of further improvements in antiretroviral drugs” (Phillips et al., 2007).

Now that there is a greater understanding of the effect of drug regimens on the body, commentators argue the benefits of starting on an HIV regimen when the CD4 cell count is at 350 cells/mm<sup>3</sup> (Phillips et al., 2007). SA's soon-to-be-revised National Antiretroviral Treatment Guidelines recommend treatment initiation when the CD4 count falls between 350 and 200 cells/mm<sup>3</sup> or when there is an AIDS-defining condition. However, when ARVs are not readily available, maximum clinical benefits accrue when targeting the most

immunodeficient. Loubiere et al. (2008) indicate that it is more cost-effective to provide HAART than to treat HIV-related OIs.

The SA government in December 2009 (South African Government Information, 2009) announced its intention to increase the CD4 threshold for starting on ART to 350 cells/mm<sup>3</sup> for all people co-infected with HIV and TB, and all pregnant HIV-positive women. Additionally, all children under one year of age will receive treatment if they test positive, regardless of their CD4 cell count. Such policy changes, state Cleary and McIntyre (2009), have major resource implications.

### ***Decreased infectivity from taking ARVs***

The test for HIV has public health value as the viral load is lowered when ARVs are initiated early, which reduces infectivity and therefore transmission (Fleming et al., 2000; Sanders et al., 2005; Bartlett & Mayer, 2006; Delpierre et al., 2007; Jaffe, 2009). Transmission to sexual partners is reduced by 20 percent. Hence, Pincus et al. (2003) describe the identification of patients with acute HIV as having a “public health benefit that cancer screening does not”. Even if a person continues to engage in unsafe sex, the chance of transmission to their partner is reduced with a lower viral load (Quinn et al., 2000).

### ***Financial costs of early testing***

The cynical could argue that when so many of the population living with HIV are unemployed, their deaths are not a loss to the SA economy. However, there is a moral imperative to make ARVs available, and to find the resources in order to do so. Additionally, Bell et al. (2003) studied the long-term economic implications of AIDS in SA, concluding that there would be a substantial loss of the government’s tax base and a complete economic collapse without a suitable response to the epidemic; the perception that it is only the poor who become infected by HIV is challenged by industrial data and the professions of teaching and healthcare (PulseTrack Healthcare Consulting, 2003).

It has been found to be cost effective to increase the number of people who know their HIV-positive status, as greater treatment provision and resultant better health negate the need for

hospitalisation and treatment for OIs (Rotheram-Borus et al., 2006). Persons with very low CD4 cell counts who start ART are more likely to need costly in-patient treatment and to die, which is not economically viable (Chen et al., 2006; Bartlett & Mayer, 2006; Maartens, 2007), as persons are lost to the workforce and dependents are left without support – a further burden on the state in terms of welfare expenditure.

There is of course an increased cost of ARV provision when more persons are identified as living with HIV. The HI virus can mutate, in which case the combination of ARV medicines initially administered (a first-line regimen) has to be changed to a different combination of ARVs (a second-line regimen). Cleary and McIntyre (2009) argue that first-line ART is preferable to second-line ART, as it is more efficient and allows all who need treatment to receive it at lower cost. They acknowledge that the provision of first and second-line ART has become a norm in SA and this status quo will not be overturned.

The unsavoury choices if there is not affordability in SA's resource-poor health system are to ration HIV treatment, or scale down or cancel other interventions. If SA is to afford a universal ARV roll-out, the huge financial burden will have to be shared by global health initiatives.

### ***Reducing the impact of stigma***

It is important to encourage “supportive attitudes and practices within communities”, so that stigmatising of people – discriminating against and stereotyping – does not stop them from protecting the self and others, thereby hindering efforts at prevention (Crepaz & Marks, 2002). Cameron (2007) speaks of the internal stigma and fear that prevents people from knowing, or in the case of Dr Ian Phillips (former ANC member and activist) and Ronald Louw (former Professor of Law at the University of KwaZulu-Natal, human rights lawyer and activist), disclosing their status.

In an open letter of condolence to the family of Phillips, the TAC urged people to test for HIV: “Finding out your status before your CD4 count drops below 200 or you develop serious OIs is the best way to ensure long-term survival with the disease”. If a large number of people know their status, there is more likely to be social pressure to reduce stigma. Likewise, the destigmatisation of HIV will reduce the reluctance of people to test for HIV (Ehrlich, 2007).

## ***Conclusion***

Whilst acknowledging the potentially psychologically harmful effects of learning about one's HIV-positive status, the empowering knowledge outweighs the negative impact, in that a person is able to make appropriate lifestyle choices and access life-giving and -enhancing treatment (Henn et al., 2006; Cameron, 2007; Maartens, 2007; Grimwood, 2007). Cameron (2006a) asserts, "One could even say it is within the duty of care to conduct a test – the alternative to death".

Transmission and therefore HIV incidence declines when PLWHA refrain from unprotected sex (Fleming et al., 2000; Crepaz & Marks, 2002; Marks et al, 2005 & 2006; Henn et al., 2006; Delpierre et al., 2007; Ehrlich, 2007). OIs can be countered even without ARVs (Ehrlich, 2007). Where ARVs are available, if diagnosis occurs early before a person becomes ill and has to be hospitalised, a considerable cost is averted to the individual in terms of life-years and the state in healthcare expenses. When engaging in unsafe sex, HIV-positive persons are less contagious as the viral load decreases with effective therapy (Kahn & Walker, 1998).

UNAIDS (2004) is unequivocal regarding the importance of testing: "Among the interventions which play a pivotal role both in treatment and in prevention, HIV testing and counselling stands out as paramount". Holbrooke and Furman (2004) add that the answer to the HIV epidemic lies in testing, which they describe as "the missing front in the battle against AIDS".

## CHAPTER TWO: THE PRACTICE OF VCT IN SA

### *Introduction*

The HIV epidemic is not abating in SA, despite massive resources devoted to prevention through behaviour change initiatives and to testing for HIV. This poses the questions of what is being done wrong and what more could be done. As the focus of this paper is testing for HIV, the present state of testing in SA – utilization of the VCT approach – will be interrogated in order to identify its shortcomings and explore solutions to the challenges.

### *The evolution of testing for HIV*

Testing for HIV has evolved in SA over time, in terms of the testing kits and therefore the methods utilised. Initially, a small sample of blood was taken from a person and was sent to a laboratory in an enzyme immunoassay (EIA) or ELISA test – the process from blood taking to results took up to two weeks and typically required two visits; the first for pre-test counselling and taking of blood and the second to receive the results and undergo post-test counselling and follow-up. This process was time-consuming, available to only a few and very costly.

The rapid test for HIV was then introduced into SA, defined by the South African DoH (2006) as “a test used to determine a person’s HIV antibodies in whole blood as well as in serum or plasma (by a finger prick) that takes about 10 to 30 minutes to perform”. An advantage of the rapid test is that results are available immediately, negating the need for a further visit. It has been found that if a return is necessitated, people fail to do so and are lost to the system. For example, a Kaiser Family Foundation (2006) survey reports that one in six people in the USA failed to return for their test results, when undergoing conventional testing with laboratory use. Bartlett et al. (2008) put this figure at up to a third of HIV-infected patients in the USA. On-site rapid testing improved the coverage of persons receiving their results at clinics in Francistown, Botswana (Creek et al., 2007), and at two Ugandan hospitals (Wanyenze et al., 2008).

The rapid test also has the advantage of being “highly accurate”, making it more feasible to test for HIV in a variety of settings (Bartlett et al., 2008). The >99 percent specificity and



sensitivity (with few false-negative results) of current HIV tests, and false positives in low risk populations of only about 1 in 250,000 are applauded by Wynia (2006). The shortcoming of false positives could be due in part to lack of quality assurance and inadequate training of nursing and lay counsellor staff by government and NGOs, plus the lack of optimal conditions for storage (Maartens, 2007). At least all positive test results are confirmed in SA – allowing for the detection of false positives – with a conventional EIA and Western Blot test.

Additionally, rapid testing costs are lower than laboratory processes (CDC, 2005), useful in SA's resource-poor setting, and the HIV test is (as the name implies) quick and non-invasive (Coetzee, 2007). It can be done in a variety of healthcare setting where laboratory facilities are unavailable, and non-laboratory personnel, such as clinical nurses and doctors, can administer the tests and share the results. Post-test counselling can happen immediately and persons can enter quickly into medical care.

For the above reasons rapid testing for HIV has become the norm in SA. So, too, has a particular approach to testing become primary in SA - Voluntary Counselling and Testing (VCT). It tests those who proactively seek an HIV test, with no active encouragement from a healthcare provider. The South African Department of Health (2006) defines it as:

*“an HIV prevention and care intervention which gives the client a voluntary opportunity to be counselled in order to explore his or her HIV risk; to learn about his or her HIV status; and to learn about other HIV and AIDS-related services and how to modify their behaviour to reduce the risk of HIV infection”.*

All tests utilising VCT require the consent of the individual and also a process of pre- and post-test counselling, of anything up to 20 minutes in the case of a negative result and up to an hour in the case of a positive result. A definition of pre-test counselling is given by the South African Department of Health (2006):

*“A dialogue between a provider and a client with the aim of preparing and assisting a client to make an informed decision about taking an HIV test”... “a health provider should recommend HIV counselling to all clients on a routine basis to ensure that all clients who would benefit from counselling and testing receive these services”.*

Post-test counselling is described as:

*“a dialogue between a provider and a client with the aim of informing the client of his/her HIV test results and assisting the client to understand the implications of the results and facilitate access to appropriate services”.*

### ***The value of pre-test counselling***

An emphasis on the word ‘voluntary’ has resulted from the response to early calls for mandatory testing of high-risk groups, particularly the already stigmatised gay population of the West Coast of USA (Richter, 2006): the three Cs – (pre and post-test) counselling, (informed) consent and (test result) confidentiality – were prioritised as a response to the “pervasive stigma, demonization and criminalisation” of PLWHA and people at risk of infection (Csete, 2006). In an era when treatment for HIV in the form of ARVs was unavailable and when there was a huge amount of stigmatization and discrimination, pre- and post-test counselling with confidentiality and written consent were vital (Bekker, 2008). This vital, protected, human rights paradigm shielded people from discrimination, exposure, disclosure and compulsory testing (Cameron, 2007).

Present-day advocates of the pre-test counselling component of VCT argue that it enables persons to be better equipped to cope with their status and will encourage them to adhere to an ARV regimen (Heywood, 2005). Others maintain that behavioural change will only result if there is adequate pre-test counselling, information and consent (Kenyon, 2005). This assertion is challenged by the findings of Weinhardt et al. (1999). Having reviewed the available literature, they conclude there is no difference in sexual behaviour for people testing negative after counselling than for those who never receive counselling. Citing the CDC’s Project RESPECT, they suggest that “enhanced” counselling with a few sessions does result in greater use of condoms and less STIs. However, they admit to weaknesses in their review of the effect of counselling, as they could only draw on meagre documentation of the diverse range of counselling techniques and length and intensity of provision.

There is a strong lobby arguing pre-test counselling has little value and is therefore redundant, particularly as the HIV landscape has changed considerably over nearly 30 years. The argument is that the human rights protections that developed around testing for HIV at a time

of association with the gay community are redundant, and persons are only dissuaded from being tested (Wynia, 2006; Cameron, 2007; Creek et al., 2007; Grimwood, 2007). Creek et al. (2007) indicate that people prefer not to engage in discussions on sexual behaviour and HIV risk that are of a highly personal nature. “It is time to abandon this ethnocentric Western rhetoric”, state Holbrooke and Furman (2004), “born in the 1980s in the United States under different circumstances that led to the ‘V’ in VCT”. Venter (2007), a harsh critic of VCT, argues it has failed because people do not volunteer, and that “denial and illness have triumphed over knowledge, as the outmoded language of human rights is still in vogue”.

The value of pre-test counselling for HIV continues to be hotly debated, as consensus has not yet been reached. There is clearly uncertainty regarding the extent that it impacts on the behaviour of persons, and there is room for this matter to be more thoroughly researched.

### ***Numbers testing***

Too few people are testing for HIV in SA and persons are therefore living without knowledge of their status. The HSRC (Shisana et al., 2009) is encouraged that the percent of people who are aware of their status rose from 12 in 2005 to 25 in 2008, but still emphasizes the need to further improve the uptake of HIV testing. Awareness of status in 2008 among African females, the highest level of awareness, was only 36 percent, with awareness among MSM at 27 percent and African males (aged 25 to 49) at 25 percent (Shisana et al., 2009). Men are a particular category who fail to test if not encouraged, even if they are aware of treatment availability (Richter, 2006).

Ignorance of status is not unique to SA or other developing nations. The situation in rich countries is not much better, if the USA case is anything to go by. A study in six cities in the USA found 77 percent of a total of 573 young HIV-infected MSM did not know that they were infected (CDC, 2003; Janssen et al., 2007). In the USA more generally, the estimate of persons unaware of their HIV-positive status is 25 percent (CDC, 2003; Glynn & Rhodes, 2005; Paltiel et al., 2005; Walensky et al., 2005a; Janssen et al., 2007). Fifty-four percent of new sexually transmitted HIV-1 infections originate from this 25 percent (Marks et al., 2006), indicating that persons unaware of their status are 3.5 times more likely to transmit the virus than those who are aware of their status.

As VCT puts the burden of responsibility to test on the client, people who perceive themselves to be without risk will not get tested. This is problematic, as such people (for example, married or widowed persons) may actually be in a high-risk category. In a behavioural survey (Shisana et al., 2005), 66 percent of respondents thought they were probably or definitely not at risk of HIV infection and more than half of those who tested positive thought they were risk-free. The Kaiser Family Foundation (2006) reports that the lack of risk perception is the most common reason people in the USA fail to test for HIV, cited by 61 percent of people never tested. Glick (2005) asserts that “considerations from behavioural models and the available data suggest that as VCT coverage expands... potential uptake among those at highest risk is uncertain”.

Although Richter (2006) describes the near impossibility in SA of being able to measure VCT impact and of knowing how many people are aware of their HIV status, the HSRC household survey figures of Shisana et al. (2009) are of concern. They reflect a low uptake of the client-initiated process of VCT (Whiteside, 2008), which results in the failure of an appropriate treatment and prevention response (De Cock, 2005).

### ***Testing too late***

Early identification of HIV allows an appropriate treatment response, which suppresses the viral load and brings about a decline in infection (Pincus et al., 2003; Frieden et al., 2005). However, the reality is that people who test for HIV often do so late, resulting in a late diagnosis. “Current approaches to testing are inadequate”, state Sanders et al. (2005), as many people at risk are not tested, and HIV-positive people are identified with advanced disease. Wanyenze et al. (2006) similarly describe VCT as a “missed opportunity to identify and refer for care many seropositive individuals”, as people without “overt signs and symptoms” of AIDS are not offered an HIV test as readily as those who present with “overt complications”.

A PLWHA in SA does not necessarily visit a health provider and therefore only discovers their status in the symptomatic phase, at which time ARVs are less beneficial (UNAIDS, 2006). This is a problem particularly among men (Courtenay, 2000). Women are more likely to visit health providers, but many only learn of their positive status when they are pregnant.

Infections of PLWHA go unnoticed by healthcare providers and others for years (Frieden et al., 2005; Akers et al., 2007), as they often make a number of hospital visits without HIV

being diagnosed (Pincus et al., 2003) and are only treated when they have AIDS-defining conditions (CDC, 2006b). Paltiel et al. (2005) argue that with current HIV testing practices in high-risk populations, 29 percent of HIV-infected people remain undetected until the onset of an OI. Bassett et al. (2007) add that although patients come into contact with the health system in SA, they are not referred for testing and therefore remain undetected with the model of VCT. Increased mortality results, as almost half of newly identified cases have an AIDS defining condition within one year.

In his work as a clinician, Venter (2007) sees people dying of AIDS because they do not discover their status in a timely manner, despite the relative availability in SA of a free HIV test and ARVs. He describes “treatment compromised” patients: “huge numbers of people tested when they are severely ill and the use of antiretroviral drugs is far more complex and less effective”. Zackie Achmat (Cheng, 2007), a leading SA AIDS activist, similarly describes “the biggest problem” as an overburdened healthcare system full of sick people who come too late for treatment.

### *Accessibility*

Particular elements of the testing process have made VCT less effectual than it should be, and have resulted in negative perceptions (Kalichman & Simbayi, 2003). There is an absence of task-shifting, which would allow (well-trained) lay-counsellors and not nurses to perform the test. De Cock (2005) criticises VCT as “onerous in time and counselling requirements”, which discourages attendance and means that fewer persons are tested. In Uganda, according to Wanyenze et al. (2006), citing the Uganda Demographic Health Survey (2000-2001), despite 72 percent of women and 74 percent of men expressing a wish to test (a number due to rise with access to ARVs), only eight percent of females and 12 percent of males knew their status due to the inaccessibility of VCT.

Young people will hesitate to go for a test for HIV if they think their guardians and others in their small community might learn of their use of such a facility. If known by healthcare providers, embarrassment may serve as a further deterrent. It is sometimes these same healthcare workers who stigmatise PLWHA and ‘judge’ the young people utilising services (Steinberg, 2008). Health workers were identified as a source of stigma in Botswana, before the introduction of RHT (Creek et al., 2007).

Valdiserri (2002) and Gruskin et al. (2008) highlight the importance of healthcare workers who are non-judgmental about behaviours of their clients, in order to allay the fear of testing and to encourage people to be tested. Arguing that people at high risk may not test in a timely manner due to previous experience of negative attitudes of the healthcare system, Valdiserri (2002) concludes that it is the responsibility of public health practitioners “to work towards minimizing the negative health consequences of HIV and AIDS stigma”. For this to be guaranteed, healthcare workers would need to receive anti-stigma workshops and training in counselling skills.

### ***The impediment of stigma***

It is internal stigma that results in “paralysed inaction, postponement, delay, denial and death”, according to Cameron (2006b). Arguing that people do perceive the act of testing to be of value, Kalichman and Simbayi (2003) suggest people do not seek VCT due to social barriers to getting tested, particularly AIDS stigma. Chesney and Smith (1999), Kalichman and Simbayi (2003), UNAIDS (2004) and Richter (2006) also state that stigmatising beliefs prevent people from being tested for HIV. There is fear of the consequence of a positive diagnosis, discrimination and the disease-death association, and there is a lack of trust in the healthcare system, states Heidi van Rooyen (2007) of the HSRC.

Observers have attributed the low uptake of VCT that occurred in Botswana after the introduction of ART in 2002 (and prior to the introduction of RHT) to HIV-related stigma. Wolfe et al. (2006) “found evidence of pervasive stigma in patterns of disclosure, social sequelae, and delays in HIV testing”. Ninety-four percent did not disclose to their community and 69 percent kept this information from their family.

People will be reluctant to get tested for HIV if their condition or the test itself is stigmatised or if the perception is that PLWHA will be stigmatised. The more people test, the more normal the process becomes and the stigma will lessen. If testing were made easier, people may be pushed to overcome their hesitation. This may create “a bridge... to cross over the perilous rapids within that were preventing... accessing medical diagnosis, care and treatment” (Cameron, 2006a).

### ***The impact of fear***

It is unclear to what extent fear of learning one's status dissuades persons from being tested for HIV. Cameron (2006a) describes people who have "access to medication, support and the assurance of acceptance and non-discrimination – yet who are too fearful, too tardy, to have themselves tested". Valdiserri (2002) highlights a number of studies showing people avoid HIV testing as they are fearful of the result and of others learning about their status. This was borne out in research conducted by Wolfe et al (2006) in Botswana. Weiser et al. (2006) similarly found 49 percent were prevented from testing by the fear of knowing their status and 33 percent were fearful of having to change sexual practices on learning of an HIV-positive status. Additionally, women avoided testing because of the fear of having to wait in a small room for hours.

Cameron (2005) asserts that the "fuss and bother" associated with the exceptionalism of VCT serves to frighten people who think they might be HIV-positive and inhibit their attendance at a testing site, constituting "a source of risk and harm": he explains that it "reinforces their own conception of the exceptional, horrific and unacceptable nature of the infection". As well as reinforcing their fears, the safeguards "accentuate also their inner disavowal of entitlement to betterment", and cause people to describe their illness as something else.

### ***The high cost***

There is an inadequacy of cost-effectiveness data on VCT provision in sub-Saharan Africa, indicate Stanley et al. (2004), as it only includes select costs, models output data and focuses on insufficient time periods. Their analysis, however, concluded that costs were higher than expected, with staff costs dominating.

Forsythe et al. (2002) explain that high cost VCT is not affordable in low-income countries, with tight health budgets, but also indicate research has not compared integrated and stand-alone services. They suggest that integration into existing services would better integrate care and prevention, particularly if staff at the health centres assume the counselling role.

## ***Conclusion***

Although more persons are testing in SA than ever before (Shisana et al., 2009), there is still a considerable shortfall in the number voluntarily coming forward, and in those achieving early diagnosis. This is the reality at a time when VCT predominates, a testing process that has been under-utilised, and can only therefore be described as “partially successful” in terms of cost-effectiveness (Maartens, 2007). Stigma, fear of disclosure and lack of accessibility have a part to play in this underutilisation (Grimwood, 2007). The VCT process is also human resource and time-intensive, largely due to the emphasis on pre-test counselling. There are some effective VCT programmes, confirmed by HIV & AIDS Treatment in Practice (2007), but “the coverage of these noble efforts is spotty at best”, and scale-up is restricted by the lack of capacity. These more successful efforts have been insufficiently replicated (Gruskin, 2005).

Since VCT is not able to adequately identify people in SA who are living with HIV, and if it is our aim, reaffirmed by President Zuma in his World AIDS Day message (South African Government Information, 2009), to accelerate the number of people testing for HIV in SA, should we rather focus on the exploration of other testing methods? One such method, the routine approach utilising rapid testing, will be interrogated in the next chapter.



## CHAPTER THREE: THE ROUTINE APPROACH TO TESTING FOR HIV

### *Introduction*

Social marketing campaigns, such as those of *New Start*, attempt to ‘sell’ VCT to the SA public. Members of the public do buy into the ‘product’ of an HIV test, but it is ultimately a waiting game – waiting for someone to consent to be tested. There has been a marked evolution in the HIV epidemic over the past 27-plus years, with ARVs now available but people still dying of AIDS. It is therefore appropriate to investigate new approaches that may result in greater numbers testing, in order “to put those who are newly-diagnosed in a position to better manage their HIV status and to enable them to access treatment when it is medically appropriate” (Richter, 2006).

It is particularly in countries with high prevalence, argue Bassett et al. (2007), including SA, that new approaches are needed for the sake of both individual care and public good. This is essentially the application of public health principles to the epidemic, which, argue Frieden et al. (2005), will “prevent tens of thousands of people [in this country] from becoming infected with HIV in the next decade”.

The focus of this chapter is the routine or opt-out approach that has been lauded by the CDC and implemented in Botswana with enthusiastic government support.

### *Promotion of routine HIV testing*

Opt-out screening is defined by the CDC (2006a) as “performing an HIV test after notifying the patient 1) that the test will be performed and 2) that the patient may elect to decline or defer testing”.

*“Routine HIV testing means that when somebody attends a government health facility with some kind of illness or for a routine check-up, they are offered an HIV test. They have to give their consent to have the test and have the option of refusing. If they test positive, they are offered counselling and appropriate treatment as necessary”*

(Cockcroft et al., 2007).

As early as 1993, the CDC recommended that hospitals and associated clinics in areas with high HIV prevalence offer HIV testing routinely to all patients aged 15-54 years (CDC, 2001). By 1998, De Cock & Johnson (1998) argued that it should be within the competency of all doctors to offer such a test.

Del Rio et al. report in the MMWR (CDC, 2001) that few screening programmes had been implemented in hospitals and clinics with high prevalence by 2001, despite the 1993 recommendations of the CDC. Concerned that newly diagnosed HIV infections had increased by 14 percent among MSM and 10 percent among heterosexuals between 1999 and 2001 in 25 states in the USA, the CDC (2003) and US Department of Health and Human Services Agencies launched 'Advancing HIV Prevention: New Strategies for a Changing Epidemic' in 2003.

UNAIDS (2004) called for an increase in the promotion of RHT in clinical settings, emphasising from the outset the importance of a human rights approach and the respect for ethical principles (They argued for a non-consensual approach only if an urgent response was required and a patient was unconsciousness). RHT was particularly recommended in the settings of: a) STI clinics or elsewhere, with counselling dependent on status; b) prevention of MTCT; and c) clinical and community healthcare, with a higher prevalence of HIV and ART availability.

As slow testing uptake continued, operational guidelines were formulated in 2006 by WHO/UNAIDS (2007) on provider-initiated testing and counselling in clinical settings, after consultation with a range of stakeholders. In response, Human Rights Watch (2007) asserted that "scaled up HIV treatment... is both a human right and public health imperative", adding that "scaling up testing should not be an end in itself" but rather a means to ensure the adoption of behavioural changes and enhances prevention, treatment and care.

CDC (2006c) at the end of 2006 recommended HIV screening for people aged 13 to 64 in *all* healthcare settings. The need for counselling would be the same as for other serious conditions, described by Bartlett et al. (2008) as "transmissible infections": the idea was not to do away with counselling, but rather to allow healthcare providers to use discernment when deciding its extent. This approach was recommended for hospital emergency departments, a variety of clinics and other primary care settings.

WHO (2007) revised its RHT guidelines after it was estimated that only 12 percent of men and 10 percent of women in sub-Saharan Africa were aware of their status. It recommended provider-initiated testing and counselling (PITC) at healthcare facilities in sub-Saharan Africa, in particular at antenatal, childbirth and post-partum health services. It re-emphasised the imperative for “timely detection” of HIV, transmission prevention and access to follow-up treatment, care and support.

### ***Botswana - a case study***

Only 17,500 of an estimated 110,000 eligible people had enrolled in the Botswana National Treatment Programme by January 2004, despite the availability of ARVs from the beginning of 2002. This shortfall was largely due to the lack of people being tested for HIV: only 70,000 of a total population of 1.7 million had tested by mid-2003 (Weiser et al., 2006). Dr Banu Khan, National Coordinator, NACA (BONELA, 2003), described the “increased desperation by medical practitioners who feel that services offered in Botswana, including the ARV programme, are underutilized due to the reluctance of many Batswana to test for HIV”.

In response, stakeholders came together in Botswana in 2003 to discuss RHT from a legal perspective. The consensus was that if RHT were introduced properly, it would be a ‘best practice’ in terms of the epidemic. It was clearly distinguished from compulsory or mandatory testing, in which there is no opportunity to decline testing. The objectives were to reach more people at an earlier stage of infection (who would be able to access services earlier), normalise treatment and remove stigma (BONELA, 2003). Dr Patson Mazonde, Director of Medical Services in the Botswana Ministry of Health, stressed “if you do not do [RHT] you are going to have a health crisis” (BONELA, 2003). After an announcement of intent by President Mogae in October 2003, RHT was introduced in January 2004 in order to increase HIV testing and ART uptake (Kenyon, 2005).

Coverage is recommended for the following categories: a) all patients presenting to clinics with clinical signs and/or symptoms of HIV; b) pregnant women attending antenatal clinics; c) patients with STIs; d) all patients aged 16 and over visiting health facilities who are sexually active; and e) any healthy individual going for a general medical exam. Additionally, repeat RHT should be offered once a year and/or upon the individual’s request. Healthcare providers are advised to give adequate information to patients to enable them to give informed consent,

but patients are not typically offered in-depth pre-test counselling. Patients may choose a rapid or standard ELIZA test and all patients are offered post-test counselling (Weiser et al., 2006).

A general assessment of RHT is provided below, with special attention given to the efficacy of Botswana's approach and its applicability to SA.

### *An increase in uptake and awareness of status*

Where RHT has been piloted, in a move away from VCT, an increase in uptake has been observed. This has been the experience in SA (Bassett et al., 2007), Botswana (Cockcroft et al., 2007; Creek et al., 2007), Zimbabwe (Chandisarewa et al., 2007), Uganda (Wanyenze et al., 2008) and Kenya (Alcorn & Smart, 2006), and in the USA (CDC, 2001; CDC, 2004a; Hamill et al., 2007; Buchbinder, 2006) and UK (Hamill et al., 2007).

Bassett et al. (2007) evaluated the yield of a RHT programme compared with traditional VCT at an outpatient department of McCord Hospital in Durban, SA. Only 32 percent tested through VCT, of whom 75 percent were HIV-positive (eight cases of HIV infection per week). Utilising RHT, 49 percent agreed to a test, of whom 33 percent were HIV-positive (39 cases identified per week). The rate of HIV detection using RHT was nearly five-times higher than when offering VCT, which convinced Bassett et al. (2007) of the value of introducing RHT in a high prevalence setting such as SA.

In Botswana's Nyangabgwe Referral Hospital in 2003 (pre opt-out), 50 percent of women knew their status at the time of discharge. In the first nine months of 2004 (post opt-out) this number rose to 76 percent. Likewise, there was an increase in the number of women who knew their status in all 24 PMTCT programme health districts of Botswana, from 52 percent in 2003 to 69 percent in 2004 (CDC, 2004b).

A study of routine prenatal HIV testing was conducted at Francistown clinics to assess the acceptance and rates of return for care. In a period pre-RHT, 75 percent of pregnant women tested in comparison with 91 percent directly after the introduction of RHT. There were also substantial increases at the referral hospital in Francistown and at clinics throughout the country (CDC, 2004b). Weiser et al. (2006) argue likewise that the introduction of RHT in Botswana brought a 15 percent increase in the number of pregnant women undergoing HIV

testing. Forty-eight percent of their Botswana sample had tested, as opposed to only 10 to 12 percent of their Zimbabwe sample, where VCT was practiced (these Zimbabwe figures were gathered in 1999).

Alcorn & Smart (2006) describe more than 60,000 tests being carried out in Botswana in 2004 after the government announced its plan to roll out RHT at health facilities. Uptake of testing increased by 134 percent in 2005, and 90 percent of those who were offered the test opted to go ahead with it; in the same year, 41 percent were identified as being HIV-positive. Additionally, over 90 percent of people who had not tested before tested at mobile clinics in Botswana after they were introduced, accounting for 14 percent of people tested in 2005.

After two years of implementation, the estimate by health officials was that 35 percent of the population of Botswana knew their status (PlusNews, 2006a). The acceptance of HIV testing increased, bringing a concomitant rise in the number of women attending prenatal care and persons receiving test results (CDC, 2004b). At the time of a Cockcroft et al. (2007) survey, over 50 percent of respondents had been for a test in the past 12 months and of these, the majority (49 percent) had been to a routine test provider as opposed to a VCT centre (42 percent). Of those offered a test, 84 percent went through with it. Additionally, Creek et al. (2007) found that RHT resulted in 78 percent of women at a referral hospital in Francistown, Botswana, knowing their status at the time of delivery, compared with the previous figure of 47 percent using the VCT approach.

The results of a study by Chandisarewa et al. (2007), at an antenatal clinic in urban Zimbabwe, show that many more women test using the opt-out than the opt-in approach: 100 percent as opposed to 65 percent. As a result, more women are identified as HIV-positive: 20 percent as compared with 17 percent.

Of people undergoing a routine test for HIV in two hospitals in Uganda who had not tested positive before, 25 percent prevalence was detected and 81 percent were being tested for the first time. Twenty-eight percent of the first-time testers were HIV-positive and of children under 15 years of age, 14 percent were positive, of whom 96 percent had never been tested before. Of family members offered an HIV test, 20 percent prevalence was detected (Wanyenze et al., 2008).

### ***Earlier diagnosis***

Almost half of those newly diagnosed with HIV learn of their status within 12 months of developing AIDS (Buchbinder, 2006). Early testing avoids such late diagnosis, when a person's immune system is already compromised. This is one reason the CDC (2006b) prefers RHT to testing based on the identification of potential risks, which would have missed a testing opportunity 79 percent of the time.

In Botswana, before the introduction of routine HIV testing, most people presented late to healthcare providers (BONELA, 2003). Stegling (2004) argues that when resources are limited, people presenting early have to wait while treatment is given to such people who are ill or have depressed immune systems. Referring to the opt-out testing now practiced in Botswana, David Ngele, a Batswana living openly with HIV, states "...people test in time [and] therefore receive necessary help before their condition worsens" (PlusNews, 2006a).

Evidence from a teaching hospital in the USA suggests RHT "detected a significant number of new HIV infections earlier than might have otherwise been" (Kelen et al., 1999). The advantage of early diagnosis of HIV infection for public health (fewer new infections) and individual health (earlier access to counselling and health monitoring) is also recognised by Bartlett (Bartlett & Mayer, 2006), Hamill et al. (2007) and Wanyenze et al. (2008).

Focusing on SA, Bassett et al. (2007) too describe the importance of early diagnosis and care in order to stabilise the HIV epidemic. However – and this is a departure from most research findings – they did not find that patients were identified at an earlier stage of infection when utilising RHT as opposed to VCT. Also, argues Francois Venter, even routine opt-out programmes would fail to identify many HIV-infected people until too late, as they would have to visit a hospital in order to be identified (HIV & AIDS Treatment in Practice, 2007).

### ***Improved care provision***

Testing for HIV is only one part of the prevention and treatment package. As Macklin (2005) states, "critical to the testing process... is systematically linking testing with existing or planned treatment or prevention programmes". And of course, care provision is only possible if the HIV-positive status of a person is known. Therefore, diagnostic purposes are the reason

to conduct PITC in healthcare settings, so that the diagnosis and management of conditions are possible (HIV & AIDS Treatment in Practice, 2007). Bartlett and Mayer (2006) state that more people enter care when HIV is “demystified”, or “normalised” as part of medical care, and more HIV-positive people are identified.

### ***A driver of ARV access and vice-versa***

Benefits of testing for HIV even when ARVs are unavailable have been discussed above. However, the availability of treatment considerably strengthens the argument for opt-out testing (Hamill et al., 2007), as policy makers are able to plan an appropriate treatment response (Rotheram-Borus et al., 2006). This is why De Cock (2006), director of WHO’s AIDS Department, stresses treatment and care should be scaled up in tandem with PITC.

Chris Green (HIV & AIDS Treatment in Practice, 2007), an AIDS treatment educator, describes the non-use of ARVs because people are unaware of their HIV-positive status as “a clear violation of human rights”. He stresses that awareness of infection should take precedence over a “right to due process in testing”, arguing that a balance is needed between human rights protections in settings of limited resources and the protection of millions of people.

Stegling (2004), Liddicoat et al. (2006), Weiser et al. (2006), UNAIDS (2006) and Cockcroft et al. (2007) argue that more people are testing routinely in Botswana because ARVs are readily available and treatment enrolment has increased. Of those surveyed by Weiser et al. (2006), 93 percent indicated that RHT would increase access to ARVs. Creek et al. (2007) later identified that AZT provision increased from 29 percent in 2003 to 56 percent in 2004 and upward to 75 percent in 2005 as RHT was introduced at four antenatal clinics in Francistown. They also found that women were more likely to know about ARV enrolment procedures if they tested routinely. UNAIDS (2006) describes a situation in Botswana at the end of 2005 when 85 percent of those in need of ART were receiving it, as opposed to less than 20 percent in SA.

PMTCT has expanded rapidly in Botswana since its 2002 introduction and has been provided as a routine opt-out test to 91 percent of HIV-positive pregnant women. Ten thousand child infections and 11,000 deaths have been averted from 2002 to 2007 (Stover et al., 2008).

On a cautionary note, Cheng (2007) draws attention to the ARV waiting list of about five million people in sub-Saharan Africa who have been diagnosed HIV-positive. The list of people needing treatment and care would only increase with the introduction of RHT, which is why the concomitant introduction of ARVs is so important.

### *A lessening of medical care expenditure*

Zackie Achmat, chairperson of SA's TAC, argues that early diagnosis and prompt treatment avoids people becoming a burden on the healthcare service (Cheng, 2007). Alcorn & Smart (2006) describe research in Uganda, which identified that "RHT shifted the profile strongly towards asymptomatic patients who needed less intensive clinical management when they started treatment". Before the introduction of RHT, 65 percent of patients had CD4 counts below 200 and three-quarters were symptomatic; however, afterwards, only 45 percent of patients had a CD4 count below 200 and only 55 percent were symptomatic.

The CDC (2006b) and Delpierre et al. (2007) concur that late diagnosis of HIV considerably escalates the costs of hospital care and management of OIs. The additional personal cost in terms of lost wages and loss to the economy of the workforce was also noted (CDC, 2006b; Chen, 2006). When Chen et al. (2006) analysed the cost of earlier diagnosis in primary healthcare in Alabama, USA, they found expenditures for patients with CD4 counts less than 50 cells/mm<sup>3</sup> were 2.6 times greater than those for patients with CD4 counts of 350 cells/mm<sup>3</sup>, as more costly non-antiretroviral medication and hospital care were required.

### *A reduction in stigma and fear*

HIV testing has been treated differently to screening for other diseases and so it has been stigmatised (Wynia, 2006), and people who are too fearful of stigma and associations with infection, disease and death, have not tested and become ill and die (PlusNews, 2006b). In response, choosing to emphasise the routine nature of testing, Holbrooke and Furman (2004) propose re-designating VCT by calling it something like 'Confidential and Recommended [or Routine] Counselling and Testing'. The CDC (2001) emphasises that RHT would serve as an opportunity to combat stigma. Stigma is reduced when testing is offered rather as a "standard of care" (Chandisarewa et al., 2007).



Referring to Botswana, Stegling (2004) describes the pervasive nature of stigmatising attitudes and behaviour or ‘othering’, even from healthcare workers. In a survey by Weiser et al. (2006), 43 percent of respondents agreed that under routine testing people would avoid going to a doctor for fear of being tested. However, 89 percent of the same respondents suggested the routine approach decreased barriers to testing and 60 percent indicated that it reduced discrimination of PLWHA.

Universal routine HIV screening is considered by the CDC (2006a) to be less stigmatizing than testing based specifically on risk, and also manages to identify people who do not consider themselves at risk or who fail to report risk behaviour. Hamill et al. (2007) and Creek et al. (2007) add that if the general population is tested in healthcare settings, no judgement is made about an individual’s risk, and this would serve to reduce stigma; conversely, identification and singling out of particular risk groups (gay men or ethnic minorities or women in antenatal settings) sets them apart and reinforces stigma. When RHT was introduced in Botswana, Dr Mazonde stressed the importance of avoiding the isolation of an individual or group (BONELA, 2003).

De Cock and Johnson (1998) and Gruskin and Jurgens (2005) argue for efforts at normalisation to be accompanied by measures, plans and actions to combat stigma and discrimination, as policy and legal frameworks have to be in place to protect people before RHT can be implemented (UNAIDS, 2006).

### ***Ensuring confidentiality***

As HIV infection carries stigma, there is potential for discrimination and even domestic violence in any situation in which there is disclosure, whether undergoing opt-out screening or VCT. The International Community of Women Living with HIV/AIDS (2005) raises the issue of violence and loss of livelihood that can result after disclosure, particularly when testing with a partner. With this in mind, Human Rights Watch (2007) “welcomes the strong emphasis the guidance of WHO/UNAIDS places on the need for confidentiality of test results and on countering stigma and discrimination”.

If RHT is utilised appropriately, confidentiality should not be an issue. In the case of Botswana, 95 percent in a survey conducted after the introduction of RHT indicated that

confidentiality was “strictly maintained” (Weiser et al., 2006). Similarly, when government health service users were surveyed by Cockcroft et al. (2007) after the introduction of routine HIV testing (RHT), 90 percent were satisfied that information about them was kept private and confidential. There was no suggestion that there had been breaches of confidentiality amongst the remaining respondents. Additionally, six percent of women in a study by Creek et al. (2007) at Francistown clinics had reported domestic violence when disclosing their status to partners after VCT, compared to none when disclosing in the RHT period.

### ***Coercion, consent and counselling***

There is concern among some commentators that the limited amount of information provided before a routine test, combined with cultural deference shown towards a doctor and an unequal power relationship, does not constitute informed consent (Kenyon, 2005; Gruskin et al., 2008). The International Community of Women Living with HIV/AIDS (2005) stresses the importance of making information available to women in particular, so that they may make an informed choice about whether to be tested. With this in mind, it is encouraging that women interviewed after RHT in Francistown, Botswana, reported no instances of being forced into testing for HIV; of those who refused to be tested, none reported a difficulty when doing so (Creek et al., 2007). The issues of coercion, consent and counselling are important, particularly as they have served to polarise the debate around testing for HIV. They merit greater discussion, and will therefore be explored further in this thesis.

### ***Cost-effectiveness***

The high cost of VCT was noted earlier, and includes the direct costs of counselling personnel and indirect costs for consumers of transportation, childcare, stigmatisation by community and psychological effects (Rotheram-Borus et al., 2006). But is there any evidence to suggest that the routine approach to testing for HIV is more cost-effective?

There is little research directly out of SA. Bassett et al. (2007) put the VCT cost per person tested slightly higher than when utilising RHT. Although the cost per HIV-infected person identified using VCT was lower than the RHT approach, Bassett et al. (2007) judged the latter approach to be cost-effective. The approach is inexpensive and accurate, and identifies a disease that can be effectively treated, bringing years of extended life. As RHT identifies more

PLWHA, it is also important to consider the cost-effectiveness of ARVs. Research in SA has found ARVs to be cost-effective (Badri et al., 2006; Cleary, McIntyre & Boulle, 2006). Certainly, the cost of ARVs has markedly declined since 1999 and the Global Fund and PEPFAR have committed considerable resources to their use (Chigwedere et al., 2008).

A number of studies conducted beyond SA, and in particular a variety of healthcare settings in the USA, suggest RHT is a cost-effective approach. The CDC (2004a), Walensky et al. (2005b) and Bartlett (2006) claim RHT for HIV in primary care, outpatient and inpatient settings is more cost-effective than colon cancer screening. The CDC described the diagnostic expense as being largely due to the need for counsellors, which would decline with the adoption of “more streamlined pre-test procedures of providing information about HIV testing”. Cost-effectiveness also compared favourably with routine screening programmes for diabetes and hypertension (Walensky et al., 2005b) and annual mammograms for breast cancer, which are “well accepted tests” (Bartlett, 2006). Frieden et al. (2005) also describe the “moderate” cost of routine screening as opposed to other health interventions, claiming more effective epidemic control could save between \$4 billion and \$5.4 billion per year.

A test would be cost-effective, argue Walensky et al (2005b), even when “prevalence of undiagnosed HIV infection is ten times lower than recommended thresholds”. They suggest the offer of RHT to high-risk groups in emergency departments. Sanders et al. (2005) argue for the expansion of routine HIV screening even when prevalence is as low as 0.05 percent, as it is as cost-effective as other “commonly accepted interventions” in healthcare settings.

Paltiel et al. (2005) compare HIV counselling, testing and referral (HIVCTR) with current practice in high-risk areas, concluding that even in populations with prevalence as low as >1 percent, “routine, voluntary screening for HIV once every three to five years is justified on both clinical and cost-effectiveness grounds”. They stress the need for existing national HIV testing guidelines to be promoted, financed and expanded. The CDC (2006b) and Cockcroft et al. (2007) also argue universal HIV screening is cost-effective in low prevalence settings, and the CDC recommends HIV screening unless the prevalence is less than one in 1,000. Besides the financial cost of screening, Pincus et al. (2003) highlight the relevance of therapy effectiveness and the probability that further infection will be reduced, when deciding whether screening is cost-effective with only one percent prevalence.

### *The need for adequate resource allocation*

The challenge of adequately training personnel and ensuring suitable resources are in place before the introduction of RHT is recognised by a number of commentators (UNAIDS, 2004; Bartlett & Mayer, 2006; Van Rooyen, 2007; Tlou, 2006; Venter, 2007; Human Rights Watch, 2007; IRIN, 2008; Wanyenze, 2008; Gruskin et al., 2008).

In Botswana, the training of healthcare workers and development of training materials were still ongoing a year after the introduction of RHT (Kenyon, 2005; Weiser et al., 2006). Implementation difficulties were exacerbated by the burden of long queues and overworked staff, for example at Gaborone's Princess Marina, the only referral hospital in the south of the country (PlusNews, 2006a). Women at clinics have failed to receive HIV test results as they are lost or delayed and counsellors are absent (Creek et al., 2007). There is also confusion about the process of who should receive a test, what information should be provided and what is informed consent, suggests Kenyon (2005), which highlights the need for a widespread public education campaign.

In an experience of introducing RHT at a district hospital in Kenya, the workload increased considerably, putting staff under stress, and privacy was compromised as space was lacking for post-test counselling. An effective response was hindered by the lack of knowledge of national guidelines and counsellor skills training (Alcorn & Smart, 2006). IRIN (2008) reports that major investments need to be made in the Ugandan public health system before RHT can be adopted nationally, including the upgrading of hospital facilities.

Chandisarewa et al. (2007) indicate that in order for widespread implementation of opt-out testing to work in Zimbabwe, "high-quality post-test counselling and adequate staffing are critical". They also stress the need for adequate logistical support and laboratory supplies, and for the community to be sensitized to the new approach through countryside public awareness campaigns. Creek et al. (2007) indicate that public education will ensure knowledge about benefits and make people aware they are able to decline both the test and treatment. As nurses are already overworked and are therefore reluctant to take on a further onerous responsibility of counselling, community counsellors would have to assume this responsibility, as funds are not available for full-time professional counsellors (Chandisarewa et al., 2007).

Bartlett & Mayer (2006) highlight the necessity for personnel to be able to provide counselling to patients on risk management and care provision, and Van Rooyen (2007) emphasises the need to broaden the range of testing personnel, providing remuneration and career paths for lay-counsellors. Counselling needs to be culturally sensitive and values-neutral, so that people are able to disclose their sexual behaviours; this is difficult when few doctors speak vernacular languages and patients do not necessarily have a good understanding of English. A prerequisite would be for health personnel to be trained “on policy, on human rights, and on public education” (Tlou, 2006). Effective health communication would also be required to ensure that people know of the implications of a routine HIV testing policy (Rennie & Behets, 2006).

Before the routine approach can be effectively scaled up in SA, there is a need for healthcare facilities to demonstrate a commitment to roll-out by providing adequate financial resources to achieve adequate testing provision with privacy and follow-up care and treatment (Wanyenze et al., 2008; Bartlett & Mayer, 2006; Gruskin et al., 2008). HIV & AIDS Treatment in Practice (2007) cautions against the introduction of RHT without working support systems for those who have learned their results. It calls for appropriate legal protections and operational safeguards so that people are not discriminated against.

### ***The importance of leadership***

“With strong, supportive leadership, prevention becomes possible; without it, it is extremely difficult”, states Whiteside (2008). Human Rights Watch (2007) describes it as a duty of the state to provide prevention services, information and ART. The success of Botswana’s testing programme can be attributed in part to its government’s commitment to fighting the epidemic, through resource allocation and a long-established treatment plan (PlusNews, 2006a); Alcorn & Smart (2006) and Creek et al. (2007) describe the positive impact of strong political leadership at the highest level, together with an effective national media advertising campaign and treatment and care provision.

Speaking during the tenure of President Thabo Mbeki, at a time when Manto Tshabalala-Msimang was Health Minister in SA, Cameron (2006b) indicated that “undivided national leadership and unambivalent commitment on AIDS” were lacking and added that “the deepest stigma impeding effective management of AIDS appears to come from the President’s

continuing unwillingness or inability to lead effectively and to speak clearly on the issue”. It is estimated that more than 330,000 lives were lost during five years of the Mbeki presidency, due to the absence of a timely ARV treatment programme (Chigwedere, 2009).

Mbeki’s successor President Jacob Zuma on World AIDS Day 2009 encouraged persons to test for HIV and indicated his willingness to take the test himself (South African Government Information, 2009). He has also committed the government to the achievement of universal access to ART by 2011, which will require an increase in testing provision. Alarm bells are sounded by Butler (2009), who suggests that as the new SA administration attempts to scale up ARV access, treatment facilities will be overwhelmed and protest politics will accelerate, prompted by the rationing of ARVs. Cleary and McIntyre (2009) describe the need for major healthcare spending increases, otherwise resources will have to be diverted from elsewhere. They describe the targets of the NSP of 2007 to 2011 as “aspirational”, as the government omitted to cost the interventions and targets, which do not take efficiency, equity, affordability or accessibility into consideration. At least there have been commitments from the international community to support the costs of SA’s ARV roll-out. The USA alone has agreed to fund ARVs to the tune of \$120 million over two years, ensuring adequate stocks to reach demand (Diplomatic Mission to South Africa, 2009).

Dr John Hargrove, director of the centre for epidemiological modelling and analysis of the South African Department of Science and Technology and the National Research Foundation, has indicated the cost of providing ARVs to all who need them in SA is affordable, and that it is cost-saving to save the lives of people. Prof Hoosen Coovadia (Professor of HIV/AIDS Research at the University of KwaZulu-Natal) identifies political will, budget allocation and proper use of financial resources as the key issues of successful scale-up (Palitza, 2009).

### ***The workability and acceptability of routine HIV testing***

Peer-reviewed literature suggests there is much client support for the routine approach where it has been piloted. When opt-out testing is offered, rates of acceptance are much higher, indicate Simpson et al. (1998), Weiser et al. (2006), Rotheram-Borus et al. (2006), Wanyenze et al. (2008) and in reference to pregnant women, Kirsche (2000) and the Institute of Medicine (2000).

Support has also come from the CDC (which wants a testing acceleration) and those who have found fault with the exceptional nature of VCT. Cameron (2006a) is a strong advocate of the routine approach, asserting that “diagnosis should be a routine and uncontroversial element in the patient management process”. Wynia (2006) favours “medical normalisation”, in order to make HIV diagnosis “at least as routine as getting colonoscopies, Pap smears, and cholesterol checks”. Gruskin and Jurgens (2005) suggest a provider-initiated model is best for a number of reasons. Some key reasons, explained by Weiser et al. (2006), are to “increase the proportion of individuals aware of their status, and thereby reduce HIV exceptionalism, lessen HIV-related stigma and provide more people with access to life-saving therapy”.

Weiser et al. (2006) found that Botswana’s routine approach was acceptable to clients and had reduced barriers to testing. Eighty-one percent of respondents were strongly in favour of such testing and eight percent indicated they were somewhat in favour. A higher 93 percent indicated that it would increase access to ARVs, 89 percent agreed the approach made it easier for people to get tested and 92 percent reported that they were encouraged to send others for testing after a favourable experience.

Cockcroft et al. (2007) randomly sampled households across Botswana to elicit views about RHT and ART. Of those surveyed, 94 percent indicated they were in favour or strongly in favour of RHT, as: a) it encourages people to get tested (68 percent); b) people can quickly access treatment (17 percent); and c) the spread of HIV is slowed (16 percent). Over 80 percent of respondents had used a government health facility in the last 24 months, since the introduction of RHT, and of these 92 percent were satisfied or very satisfied with the visit and 96 percent reported being treated with respect. In another study in which antenatal care clients were interviewed, Creek et al. (2007) failed to identify from them any adverse consequences from the introduction of RHT in Botswana.

Client satisfaction was also evident in a survey of women receiving routine opt-out testing at an urban antenatal clinic in Zimbabwe (Chandisarewa et al., 2007). Ninety-nine percent understood why blood was being taken, 98 percent felt prepared for the receipt of positive results and 99 percent were satisfied with information provided in order to effectively manage their health. The number of women attending the antenatal clinics or receiving their test results did not decline. On the contrary, 89 percent of women reported they were empowered concerning rights and responsibilities, “by accessing relevant information to make informed

decisions about PMTCT and infant feeding”. A higher number of women and infants received prophylaxis than in a period of opt-in testing, and more women enrolled in a mentorship programme, joined a support group, and attended the clinic with their babies for follow-up.

Nakanjako et al. (2007) are also quick to recommend RHT and counselling (RTC) as the standard of care in a Ugandan hospital emergency unit, describing it as a device to scale-up diagnosis and “an entry point to comprehensive prevention and care”: 95 percent of patients offered RHT accepted and 99 percent indicated it should be permanently integrated, with 86 percent asserting that it would help linkages to care for ART and treatment of OIs.

In a later study, Wanyenze et al. (2008) reaffirmed the acceptability of HIV testing and counselling when they collected data at two large tertiary hospitals in Uganda. RHT and counselling for HIV had been introduced in November 2004. Of those persons offered a test, 98 percent accepted. Of those refusing, 21 percent agreed to be tested after their illness improved and 20 percent indicated they were already aware of their HIV-positive status. When family members were also offered an HIV test, 93 percent accepted, of whom 73 percent had never before tested. The authors do caution, however, that the high rate of acceptance could be due *partly* to testing being made available gratis, which is already the case in SA.

There is support in particular for the introduction of RHT for pregnant women. Research in SA by Bassett et al. (2007) shows that significantly improved case findings come from the routine offer of a test, rather than “testing based exclusively on physician assessment or pregnancy status”. With PMTCT, uptake is 91 percent and transmission is down from about 30 percent to six percent, and the number of people on ARVs is 70 to 85 percent.

## ***Conclusion***

Advocates of RHT concur that with ART increasingly available, there is every reason to accelerate the utilisation of this approach (Jaffe, 2009). The CDC, UNAIDS and WHO have committed to its promotion, particularly in high prevalence settings, of which SA is one. Research has described the approach as cost-effective.



For such an approach to work, confidentiality must be ensured and the test must be offered without coercion, in spite of relationships of inequality between healthcare providers and clients. Of considerable importance is adequate resource allocation and training of personnel before such a system is introduced. Additionally, there is a role for leadership within government to ensure acceptability by clients.

In Botswana public acceptance of RHT and government support have been high. The numbers testing and becoming aware of their status has grown and earlier diagnosis has allowed for more cost-effective medical management and better health. Provision of ARVs has importantly come hand in hand with the expansion of this approach.

The question remains, however, of whether this approach to testing is replicable in SA. After describing my research methodology, I will proceed to detail the responses of my informants who were interviewed about the most appropriate way forward in SA.

## CHAPTER FOUR: RESEARCH METHODOLOGY

### *Overview*

This thesis has been based predominantly on a review of significant literature pertaining mainly to testing for HIV, and interviews with key informants at the forefront of prevention and treatment of HIV and AIDS in SA.

I embarked on a literature review for a variety of reasons. I wanted to focus on the most credible and updated sources of information, particularly with regard to RHT, the practice of which has grown substantially over the past few years. My intention was to build on existing knowledge and ideas and at the same time identify where there may be gaps in the literature. It was important for me, when positioning my work, to have an intellectual context for the content, and to be able to provide divergent viewpoints.

Much of the reviewed literature is particular to the USA and Western Europe, where prevalence is far lower and healthcare capacity is much greater than in SA, the primary focus of this research. Additionally, there are differences in the population groups affected and the clade of the virus. Despite these acknowledged shortcomings, the literature is utilized due to the scarcity of data from the numerous HIV-related interventions in SA (and sub-Saharan Africa as a whole, for example regarding cost-effectiveness). The experience of RHT has been under-researched in SA and there is a paucity of evaluations pertaining to the country's experience of the practice. There too are few complete reviews of VCT. Importantly, when examples are drawn from literature external to SA, and even to sub-Saharan Africa, there is clearly relevance and applicability to the local context.

I have only drawn on external literature when it is clearly relevant and locally applicable. Where possible, Western examples are balanced with the experience of sub-Saharan Africa, more specifically Botswana, Zimbabwe and Uganda. It is important to recognise that these countries, even those bordering on SA, have differing contexts, with regard to population density, resources, cultural factors and more. Even within SA, there are inequalities across the health system and disparities exist between public and private provision and between rural and urban populations. Resources are located predominantly within urban centres and allocation also differs substantially between provinces.

Following a thorough literature review, I required a more direct, individual and localised experience of testing for HIV. I therefore chose the qualitative approach of semi-structured interviews with South Africans who are experts in their respective fields. I sought first an understanding and then a deeper insight from local practitioners, in order to learn what they thought about the topics. Their descriptions in interview were in vivid detail, with a richness and complexity of personal experience that translated into valuable case study examples.

The approach of open-ended interviews allowed me to appropriately tailor further questions. I was able to probe the culturally relevant responses, as well as personal histories and perspectives. These were quite unique, particularly as the strong personalities of the individual respondents came to the fore. For some, an impassioned response was born out of frustration at what they perceived to be a lack of progress or limitations in the present approach. All respondents agreed to be publicly identified, with none appearing to be concerned with the need to maintain anonymity.

After each interview I was able to return to the existing literature, much of which although relevant to SA is the experience from elsewhere, with a fresh perspective. Information gleaned from my respondents assisted me to uncover relevant and interesting theories and hypothesis, and gain something of an insight into the diverse range of responses to this rather difficult and controversial topic.

It was important for me to select a broad base of key informants for interview, when eliciting opinions and beliefs. They included public health professionals (clinicians, epidemiologists), academics (physician, health economist), service providers (nurses, occupational health professionals), and a prominent PLWHA. All were able to provide in-depth qualitative information on the VCT response to HIV prevention, as well as alternative approaches, including RHT for HIV. This is because their expertise is informed by their roles of clinician, healthcare professional and affected person. As they are on the frontline of responding to the HIV epidemic in SA, they were all able to draw on practical experience and invariably the most current processes, best practices or techniques under trial when discussing the challenge of an appropriate testing response.

All informants responded in an unstructured style and recordings were transcribed. Although they have differing areas of expertise, issues raised were similar and there was often a consensus regarding the most appropriate HIV testing methodology for SA.

### ***Informants***

Dr **Linda-Gail Bekker** is a physician, currently located in the Institute of Infectious Diseases and Molecular Medicine (IIDMM) on UCT's Medical School campus. She chaired the SA AIDS Conference in 2009. She is a principal investigator at the Desmond Tutu HIV Foundation (DTHF), established in January 2004 under her directorship and that of Professor Robin Wood. The Foundation is well known as one of the first public clinics to offer antiretroviral therapy to PLWHA. More recently, the Foundation extended its activities to include HIV treatment, prevention, training and tuberculosis treatment monitoring in the hardest hit communities of the Western Cape.

The DTHF is one of the leading research organisations in SA, which seeks innovative ways to provide HIV testing, explores the interaction between HIV and TB and tries to find ways to prevent HIV, particularly in vulnerable groups. A goal of the DTHF is to impact policy and outcome, through evidence based methods, peer review publications and dialogue with community and service providers. Bekker is outspoken in advocating for a public health intervention on a scale that the SA HIV epidemic demands. Her key research interest is the host response to tuberculosis infection and an important recent initiative of the DTHF is the trial of a mobile HIV testing station, called the *Tutu Tester*.

Constitutional Court Justice **Edwin Cameron**, previously a Supreme Court of Appeal Judge, is the first senior SA official to have stated publicly that he is living with HIV/AIDS. He was inspired to publically disclose after the stoning and stabbing to death of Gugu Dlamini when she declared her HIV-positive status. Cameron is also a prominent gay-rights activist.

At Oxford University, Cameron researched 'Aspects of the AIDS Epidemic, examining in particular the denialist stance supported by SA President Mbeki'. Whilst employed as a human rights lawyer at the University of the Witwatersrand's Centre for Applied Legal Studies (CALS), he co-drafted the Charter of Rights on AIDS and HIV, co-founded the AIDS Consortium and founded and was the first director of the AIDS Law Project. He is presently

the Patron of the Guild Cottage Children's Home, of the Soweto HIV/AIDS Counsellors' Association (SOHACA) and of Community AIDS Response (CARE). He is the author of the award-winning book, 'Witness to AIDS'.

His dedication to advocating for human rights and championing the cause of HIV and AIDS has won him many awards and distinctions, including the Nelson Mandela Award for Health and Human Rights, Transnet's HIV/AIDS Champions Award and the San Francisco AIDS Foundation Excellence in Leadership Award. His reflections on the impact of stigma and his impassioned call for the de-medicalisation of HIV were discussed in interview.

Dr **Susan Cleary** is the Director of the Health Economics Unit at UCT, where she has been since 2001. She holds a Bachelor of Arts degree in Economics and English, a Masters in Economics and a PhD in Health Economics entitled 'Equity and efficiency in health and healthcare for HIV-positive adults in SA'.

Cleary convenes the Postgraduate Diploma in Health Economics and coordinates and teaches on a number of modules on the Masters in Public Health, specialising in Health Economics. She is also the coordinator of the Health Economics and Policy Network in Africa - a network that aims to develop health economics capacity through working with academic institutions and policymakers in eight African countries. Her research focuses in particular on the economics of HIV treatment and prevention, primarily in the areas of equity, efficiency and the costs of scaling-up. I interviewed her on the cost-effectiveness of testing and ARV provision in SA and resource allocation in the health system in general.

Dr **David Coetzee**, the founding director of the Infectious Disease Epidemiology Unit in UCT's School of Public Health and Family Medicine, is a public health specialist and epidemiologist with many years operational experience in primary care and infectious disease service delivery. He has led a number of clinical epidemiology research projects in the areas of tuberculosis, HIV/AIDS, immunisation and STIs. He was able to draw on his considerable experience as a clinician at the Médecins Sans Frontières (MSF) clinic in Khayelitsha in the Cape Town metropole.

Dr **Rodney Ehrlich** is a professor at the School of Public Health and Family Medicine at UCT. He is a senior specialist at the Occupational Diseases Clinic, Groote Schuur Hospital, and the Department of Health in the Provincial Government of the Western Cape. His

research interests include the epidemiology of chronic lung disease, including tuberculosis; social epidemiology; and occupational and environmental health, including diagnosis, treatment and compensation of occupational disease.

Ehrlich consults to the Division of District Health Services and Programmes, Department of Health, Provincial Government of the Western Cape and is a member of the Executive Council, College of Public Health Medicine of SA. His special education interests include occupational medicine and public health; research methods, social epidemiology and epidemiology of non-communicable disease.

Dr **Ashraf Grimwood** is an HIV clinician and chairman of the National Aids Convention of SA. He was Cape Town's Principal Medical Officer and then a director of Secure the Future, a philanthropic project of Bristol-Myers Squibb dedicated to responding to the AIDS epidemic in southern Africa. He has commissioned HIV research that impacts on public health policy.

Together with Zackie Achmat, known for his advocacy role with the TAC, Grimwood helped start community healthcare in the poor area of Bellville South. He was formally educated in public health in Australia, setting up the Tasmanian Aids Clinic in 1989 and later heading the Tasmanian Aids Council.

Grimwood is the executive director for ARK in SA, which treats HIV-positive caregivers and is expanding its antiretroviral (ARV) treatment programme for children. ARK works in public health institutions, introducing to the system doctors and nurses with HIV/AIDS expertise as well as pharmacists.

Dr **Gary Maartens** is associate professor in the Division of Clinical Pharmacology within the Department of Medicine at UCT, who founded and now heads the HIV Clinic at Groote Schuur Hospital. He trained in Cape Town and completed an infectious diseases fellowship in Birmingham, UK. He has served in hospitals in the UK and SA and has held the positions of medical officer and registrar. He has published widely in the field of infectious diseases and serves on local and national health policy committees. He was asked to draw on (in interview) his clinical experience of HIV management.

**Margie Tainton** holds the position of Organisational Health & Retirement Manager in the Human Resource Management Department of UCT. Her colleague, **Ashley Taylor**, is Organisational Health and Wellness Advisor in the same department. They have been instrumental in rolling out a programme of holistic health screening for staff at the institution.

University of Cape Town

## CHAPTER FIVE: DISCUSSION – ADAPTING TESTING FOR HIV IN SA

### *Pre-test counselling and human rights*

All informants agree there is considerable value in testing for HIV. However, they are not overly impressed with the VCT response. Those who have regularly met over a number of years with clients to conduct HIV testing generally see little value in pre-test counselling.

Some informants suggested pre-test counselling should be kept to a minimum, as resources are few and time is scarce in the health system. There would only be benefit in briefly discussing worries and giving reasons for undertaking the test (Ehrlich, 2007; Maartens, 2007). Ehrlich (2007) states time and resources are not available to engage patients in a hypothetical space before a test, or to tell people to rather go away and think about why they should get tested.

Others argue for the complete elimination of pre-test counselling. Cameron (2007) speaks of “the almost comprehensive failure” of VCT and describes a misconception that it is voluntary; this suggests people with HIV or at risk of transmission are going to make an excessive effort to present themselves for testing. He calls this abnormal and indicates that people do not volunteer for something normal:

*“you cannot talk about normalising HIV in an abnormal situation, I realise that... so one’s trying to lance a paradox, to breach a paradox... that HIV is still highly abnormal”.*

As ARVs are more freely available, there are increasingly calls for HIV to be normalised and regarded as a chronic (treatable) medical condition. Cameron (2007), arguing that his human rights colleagues are battling to shift from an outmoded paradigm, argues that the exceptional response of pre-test counselling is inappropriate, as the condition it screens for is comparable to insulin dependent diabetes, a heart rate issue or chronic hypertension. He states that, as SA has the biggest public sector-provided treatment programme in the world, the need is to encourage and not discourage persons from getting tested. To him, VCT is an incorrect approach, in theory and principle, justified only when no treatment is available. He indicates that people prefer not to be tested when the exceptional and unusual nature is emphasized, which amount to “exceptional burdens on the healthcare provider and the care seeker”.



Grimwood (2007) and Bekker (2008) similarly state that pre-test counselling should be merely consent, rather than working on various scenarios, as the client may be HIV-positive or negative. As much of the counselling is about information, states Grimwood (2007), people who have tested before do not need to go through pre-counselling again. Bekker's understanding, much like that of Maartens (2007), is that time can best be spent after a test describing what can be done for the person who is either HIV-negative or positive.

Bekker (2008) questions whether pre-test counselling is actually working against us, in that we continue to create an illusion of secrecy and contribute to the stigma and the discrimination in the name of confidentiality. She goes so far as to suggest that in the name of safeguarding peoples' privacy rights, we have actually completely undermined their rights to health and good care.

Maartens (2007) suggests that the approach to testing for HIV is something that SA has not fully grappled with, despite its identification as a key issue. Tension remains between human rights advocates and public health practitioners. He indicates Botswana has led the way, and that the South African Department of Health needs to take up testing more seriously and more properly.

All informants responded passionately to the contentious issues of coercion, counselling and confidentiality. Maartens (2007) accepts that human rights advocates are wary about opt-out testing, as they do not want the rights of people to be eroded, but stresses the need to be pragmatic. He acknowledges it would be coercion if a doctor argued that s/he would not treat someone unless they agreed to a test, but emphasises that patients generally come to hospital to be helped, and when they realise their condition is serious they are open to testing. He admits to pushing people hard on occasion to get tested, but asserts he has never coerced or refused to treat anybody.

Maartens (2007) states if a person is unable to provide consent, a doctor orders an HIV test, in the same way s/he would remove a clot on the brain without insisting on consent. He would essentially do what is in the interest of the patient, going about the testing process thus: if a patient has lost a lot of weight, he would consider the cause to be thyroid disease, cancer, AIDS, TB, anorexia, or perhaps a mal-absorption complaint. If there were no obvious symptoms, he would run a series of tests to narrow things down. He would not state to the

patient that the blood he is pulling is for their thyroid. However, if it were positive, he would indicate they have an overactive thyroid gland and he would have to do a particular procedure. He questions why he should not do the same for someone with HIV.

Bekker (2008) describes 70 percent of the patients in the medical wards at Groote Schuur being HIV co-effected. She indicates that if it was known that the same percentage had prostatic carcinoma, a prostate specific antigen (PSA) would be performed, yet the response of screening is not automatic. Rather, “we stand around, we dance around, some of them (the patients) are semi-comatose and we institute ridiculous care”. She has not experienced a person refusing to be tested for HIV and feels if it is marketed appropriately it is acceptable to people, in the same way that it would be acceptable to remove an appendix that is about to burst. She believes in taking responsibility to use the information that a doctor has to hand, whilst at the same time respecting peoples’ privacy and right to confidentiality.

There are opportunities for exploitation, accepts Bekker (2008), for example when commercial sex workers are abused in Indonesia because they need to be tested. However, she explains that this is not about the test but rather a country with flawed human rights. She sees the issue around consent as a “gatekeeper” to giving people better care: “People can volunteer and go get tested, but for some reason they’re not, and that’s because we’re continuing to collude that there’s something unusual about this test verses getting a blood pressure test or getting your prostate checked... it shouldn’t be... it’s a medical condition that has a treatment”. She stresses the need to pursue the normalisation of HIV.

Ehrlich (2007) emphasises the need to obtain consent, making sure there is sufficient time for essential post-test counselling and to focus attention on preparing someone who is HIV-positive. For someone who is HIV-negative, the healthcare provider simply needs to indicate that this is an opportunity to stay negative and give two or three key messages. He states that opt-out testing works when a doctor uses the levers of authority to get people through the system: “It just doesn’t work with a highly elaborate consensual model”. He questions whether on balance this is a good idea, adding that if we are to make testing work, it is important to weigh up interventions and the prospect of big gains against insubstantial costs.

Cameron (2007) objects to the word ‘coercive’, finding ‘directive’ more appropriate: “When your doctor says I’m going to put you on Aspirin and Bactrim® and a better diet, s/he is being

directive”. He emphasises that talk of coercion melodramatises the situation; coercion is a doctor saying s/he is not going to treat you unless you do an HIV test, and if it is positive s/he is not going to treat you at all. Importantly for Cameron, the change to testing that he advocates assumes protection from discrimination, beneficent healthcare providers and the availability of treatment.

### ***Stigma and confidentiality***

Cameron (2007) describes AIDS as “probably the most stigmatised disease in human history”. This is despite the fact that there is no possibility of contagion – unlike tuberculosis, bubonic plague and leprosy – and “even though transmission can occur only under well-defined, exceptional circumstances”. He adds that efforts at prevention have been disabled by “the inner feelings of contamination, shame and self-disentitlement”.

It is difficult for Cameron to comprehend why, despite knowledge of treatment for more than 12 years, affordable treatment for upwards of five years, and a public commitment to treatment in November 2003 by the SA government, and in Botswana from 2001, stigma is still so prevalent. He surmises it is due to the link between sexual transmission and internal stigma, which “is totally under-examined, totally under-researched, totally under-understood”. He suggests that VCT, because of the burden it places on the care-seeker, does not deal with this question.

Grimwood (2007) stresses that a testing service has to be anonymous enough for someone to be tested without confidential information being made public. He illustrates this point by describing a little clinic in a small village in which all inhabitants know one another. At least with RHT, when the testing facility is not set apart from the rest of the healthcare facility, there is less likelihood of the community knowing why a person is going to see a healthcare provider. However, whichever system of testing is utilised, a stressed healthcare system does not provide a conducive environment (Bekker, 2008).

### ***Leadership***

All respondents indicate the role of leadership is important in securing the acceptance by the public of HIV testing. Bekker (2008) acknowledged the value of a campaign like Komenani

under the Mbeki Presidency, but decried the absence of leadership from the then South African Department of Health under Tshabalala-Msimang. She wanted to see the President standing up and having an HIV test, which Jacob Zuma has now done (South African Government Information, 2009), in addition to his family, the Health Minister and others. Grimwood (2007) is also critical of the “fantasy, fear and obfuscation”, when the need is rather to normalise HIV; to talk openly and bluntly about the risk activities and about getting oneself tested, knowing one’s CD4 cell count and getting oneself onto treatment. Additionally, he emphasises the need for regular and consistent campaigns in the media, by Komenani and others, rather than irregular and sporadic efforts.

Coetzee (2007) argues that people failed to test under the government of Mbeki because testing had not been taken on at a political level, due to associations with stigma. He argues that VCT has not failed in itself, but rather that its lack of success has been due to the historic insufficiency of leadership and the denying and ignoring of HIV. Ehrlich (2007) adds that the disease has consistently been re-stigmatised, with a historic absence of leadership and openness. He argues that to diminish the stigma we need not only individual and contextual change, but also strong political leadership.

Bekker (2008) argues that if people consider something to be ‘kosher’, they adopt it. Therefore, she feels if more role models (celebrities, sports personalities, influence-leaders, including politicians, academics, business persons and religious leaders) step up and say this is the way to go, with an explicit endorsement, more people may test. The benefits and value need to be clearly stated. Maartens (2007) also highlights the need for bold leadership at national level, particularly as there are huge disparities in terms of treatment provision between all provinces in SA.

### ***Expanded testing effort***

The consensus from a literature review is that a “greatly expanded testing effort” is needed to impact the transmission of HIV (Marks et al. 2006), but questions remain as to the most appropriate response. There too was a consensus among informants about the value of adopting a number of approaches, but also a general feeling that VCT should not be discarded altogether. Maartens (2007) cautions against throwing out VCT, suggesting it could be done more cost-effectively in resource-poor settings – for example, by showing a group a video:

“We need to really interrogate what we mean by how much time and how expensive is it and if it is too dependent on trained staff, then what other creative ways can we use to implement it?”

### ***Mandatory testing***

Informants chose to grapple with a handful of alternatives to VCT. I alluded in interview to Francois Venter’s controversial call for mandatory testing of all South Africans in a Sunday Times editorial in 2007, born of the frustration and despair he was experiencing as colleagues were needlessly dying of AIDS. He describes a “collective denial about HIV” that was stopping people from getting tested.

Venter proposed a universal testing policy, utilising incentive-linked systems, or testing by compulsion and having to present proof of a test when applying for papers and services, such as drivers’ licences, bank cards, marriage licences and pensions (HIV & AIDS Treatment in Practice, 2007). He argued that this would place the onus on the individual and that legislating for such testing has precedents, including the wearing of seatbelts.

In literature, Mark Heywood of the TAC is forthright in his response to Venter’s call: “The suggestion that we should introduce some sort of coercive thing, that’s pushing it ridiculously” (HIV & AIDS Treatment in Practice, 2007). Van Rooyen (2007) asserts that the mandatory approach only serves to increase stigma and does little to encourage behaviour change.

Bekker (2008) supports people being tested at significant life moments, such as when entering school and employment - if acceptable and accessible - but acknowledges that SA is not yet ready. She suggests Venter is playing devil’s advocate to get the debate going when he calls for mandatory testing. His primary aim is to get people thinking innovatively, with the end goal of getting people into care and more effective service provision. Mandatory testing has not been extensively debated in SA, which is perhaps partly due to a strong emphasis in the constitution on the protection of individual rights.

### ***Routine HIV testing***

Regarding the opt-out approach, Grimwood (2007) and Coetzee (2007) suggest the “spirit” of RHT has in fact been in operation in SA for a number of years, in STI clinics, TB clinics and with PMTCT. If a nurse or doctor has diagnosed TB, which would indicate a likelihood of HIV, the need for testing is proposed. However, Grimwood (2007) indicates that protocols are followed to the ‘T’, which becomes problematic as testing is prevented from happening. He would prioritise normalising HIV testing for all pregnant women, as they have been participating in a high-risk activity (sex without a condom) and so they may have been exposed to the HI virus. There is also risk of an STI, such as human papilloma-virus or herpes simplex. He sees this as a valuable use of resources, particularly with SA’s high prevalence rate, but would not even discount the possibility in lower prevalence settings such as Britain.

Cleary (2008) suggested the targeting of RHT at “hot-spots” would be most beneficial – and states that everyone knows where the worst prevalence is. She describes equitable service provision as a situation in which one targets where there is most need and where the biggest numbers can be reached, rather than spreading limited resources so thinly that there is no benefit. She acknowledges this controversial approach would challenge the right (enshrined in the constitution) of all South Africans to healthcare provision.

Maartens (2007) and Ehrlich (2007) are very sympathetic to the opt-out strategy for certain categories of individuals, where there is an immediate benefit to their health. They recognise the value of targeted testing, emphasising that everyone with TB and those coming for reproductive health services should undergo an HIV test. Ehrlich states this is not happening enough, although he does suggest the profiling of people could become problematic, as selective, opt-out targeting could become racially based. Targeted testing could be effective if linked to likely medical presentations, such as OIs. He indicated that when he was an intern, a syphilis test was done as a matter of course when a person was admitted to hospital – there was no profiling; it was done as a public health measure, with the opportunity of diagnosis and treatment. Similarly, HIV is easily diagnosed and treatable. Maartens (2007) indicates the Western Cape already does targeted testing for persons visiting TB clinics and describes this as a very good way to focus on people who need care.

Grimwood (2007) and Maartens (2007) would also test persons presenting with STIs, as they would have had unprotected sex and be at risk of HIV infection. Adopting a public health stance, Maartens (2007) speaks of insufficient efforts to date to offer testing to every person who is entered into primary care for an STI. He recognises that testing becomes more difficult at the hospital level, when there are so many infections presenting in a number of ways.

Maartens (2007) states RHT for HIV has an immediate benefit for the infant *and* the mother, in terms of treatment interventions. For pregnant women, it is not to their benefit so much as to the baby's, but most women would likely see that as an immediate health benefit. Therefore, when the standard VCT approach does not reach this population group, as is the case in a number of provinces in SA, the opportunity is there to take blood and test for HIV, with an opt-out option. When targeted at the specific patient population, there are both public health benefits and more direct benefits to those specific groups.

This diagnostic approach is endorsed in literature by De Cock (2005), for example at health facilities in high prevalence settings or with TB patients. Hausler et al (2006) indicate that if prevention and care interventions for TB and HIV are linked, the estimated costs of preventing TB are less than previous estimates of costs of treatment. Where targeted or risk-based testing becomes problematic is when there is no perception of risk. When this perception is absent, people fail to go to be tested (Bartlett, 2008). This is why persons suggest a combination of approaches – targeted testing and broad-based screening campaigns (Marks et al., 2006).

Coetzee (2007) indicates that “champions” at some clinics are adopting the routine approach and both the voluntary and provider-initiated approaches are necessary. Maartens (2007) would preserve the walk-in clinic, complete with counselling, where a healthy person walks in out of curiosity and wants to be tested. He also believes in supporting any strategy that would improve the rate of testing and not have any negative outcomes.

Ehrlich (2007) suggests a number of systematic approaches to testing. Opt-out opportunistic testing – as a public health measure, without targeting – would be suitable when there is no obvious indication: for example, drawing blood when one goes for a tonsillectomy. Additionally, doctors could try to identify at-risk patients, for example those with pneumonia or chronic diarrhoea.

Although Maartens (2007) has reservations about RHT, he is sympathetic to such an approach for sick patients or antenatal women, provided it is done with good post-test counselling and does not ride roughshod over patients.

### ***Home testing***

I asked informants whether other approaches are workable. Grimwood (2007) feels home testing might work in SA if it were done by properly trained personnel, with test kits approved by the Medicines Control Council. He emphasises this, as the use of faulty test kits has resulted in false positives, and indicates that if community care workers were properly trained, home testing might be an option, more particularly in deep rural areas. This is an approach that has been under-researched, but a detailed analysis is beyond the scope of this thesis.

### ***Wellness screening and mobile testing***

Ehrlich (2007) and Bekker (2008) explain as critical the need to reach the population of men that generally do not go to see healthcare providers. They emphasise that there is a need to achieve community acceptance, and to rid stigmatising attitudes, and this could be achieved by the integration of testing into other care. Bekker (2008) suggests the test should be brought to them at workplaces, or wherever they are, which would make testing accessible. She reasons that in a country in which one in three adults in some communities are infected with HIV, there is every reason to bring testing to where there are large numbers of 20 to 50 year old adults, or the high-risk 15 to 20 year old adult grouping.

Bekker (2008) stresses the need to instil in the SA populace, which does not consider prevention strategies sufficiently, the need to test for HIV as a formality. She would attach it to lifestyle or 'wellness' – living long and healthily – so it becomes just like having one's blood pressure or sugar level tested. She would emphasise testing to stay healthy, rather than to protect one's partner, and stress the benefits of getting into care earlier and living longer, and if HIV-negative, staying negative. She stresses that an offer of testing needs to be simple and easy, with little time involved – so the workplace is a good location at which to test, as it is accessible. She also states that a new way of thinking is required, in which the individual takes responsibility for their own wellbeing to a greater degree than has traditionally been the case; a new dispensation where people think for themselves and where testing is made more



accessible.

Wellness initiatives involve health screening for common lifestyle diseases, including HIV, Hypertension, Hyperlipidaemia (Cholesterol), Diabetes and Body Mass Index or BMI (Obesity), with a finger prick for blood and a maximum of only 20 minutes duration. Not unlike a routine approach, there is seldom emphasis on pre-test counselling. The effectiveness of this approach and reasons for its success are explained below using the case study example of UCT.

VCT was offered to staff at UCT until early 2007 and uptake was low, despite attendance being encouraged by blanket communication and industrial theatre. Margie Tainton (2007), UCT's Organisational Health and Retirement Manager, describes "a handful trickling in": 10 to 20 per session. The most successful VCT uptake was at UCT's Graduate School of Business, where leadership actively encouraged participation. When a small sample was asked why staff were not testing at UCT, most respondents replied they were sure of their negative status and did not consider themselves to be at risk. Only 353 people (or fewer, as many were retests) of an eligible 3,000 and a target of 850 had been for VCT from 2003 to 2005, at a considerable financial cost to the institution. The low uptake encouraged the establishment in 2007 of a pilot wellness initiative. Tainton (2007) explains that in providing five tests and an option to opt-out, "there is no measure of forcing" and "we are hoping they will think, well, I may as well have all of them... with only one prick of blood".

This effective utilisation of resources does not emphasise testing for HIV per se, but rather wellness and lifestyle testing, in an effort to destigmatise HIV and make it similar to other manageable chronic diseases. The provision does enable early detection and management of HIV, although the client may opt out of any test. It is about the client taking responsibility for their health. In one department - the Office of the Vice-Chancellor - over only 2 days in 2007, 119 people came forward for wellness testing, with only four opting out of the HIV test. The experience of subsequent interventions, until September 2008, was of 86, 92, 94 and 100 percent uptake: the lowest opt-in of 86 percent may be explained by the fact this was a one-year follow-up in a department already tested.

Ashley Taylor (2007), Organisational Health & Wellness Advisor at UCT, explains that people go into pre-test counselling knowing most of the information, so it is just a matter of

refreshing it with them. The main concern is post-test counselling and getting a person safely to the counsellor and into care. The wellness initiative will move through Faculties at UCT, so that all staff are given an opportunity to test. They are likely to opt-in, as the tests are brought to them, confidentiality is assured and the service is not stigmatised (the test is a healthy thing to do – part of a holistic “wellness package”).

Attendance is incentivised with the gift of an “I know” bracelet and the offer of Vitality points that translate into medical scheme benefits. As permanent staff at UCT are obliged to join a medical aid scheme, treatment is available as a prescribed minimum benefit at no extra cost and significant savings have been made by changing the service delivery model.

Bekker (2008) stresses the importance of approaching therapy in a more managed way, rather than through crisis management, when a person learns their HIV-positive status when they already have TB or Cryptococcal Meningitis, for example, and a CD4 count at virtually zero. She indicates that people need to be identified at the time at which they are HIV-infected, but not diseased, or infected but not symptomatic, and entered into care, with a thorough monitoring of their CD4 cell count. She asserts that VCT fails to achieve this, as it relies on people coming forward because they are sick and their immune systems are already compromised. It is harder to put such people on treatment, and often more expensive, as medical care (and hospitalisation) is required.

In response, her DTHF has from May 2008 offered testing for HIV to various communities in the form of a *Tutu Tester* mobile clinic, along with screening for other chronic conditions of hypertension and diabetes, as a way to normalise the test: “The concept represents the DTHF’s vision that HIV should become viewed as a chronic treatable condition rather than one attached to stigma, discrimination and shame”.

Follow-up provision is immediate. Those testing positive receive a CD4 count test (which only takes ten minutes), in order to assess whether ARVs are required, TB screening, some STI screening and a pregnancy test – intelligent referral and comprehensive treatment. In this way, testing is taken outside clinical settings and the mobility takes it to clients who might otherwise not be reached, who are not ill.

The nature of testing as a self-initiated activity serves to further normalise the testing process, and it is highly accessible, flexible, fast and efficient, serving to encourage people to test regularly (the mobile facility returns to the same location every three months). Risk reduction counsellors offer goal-oriented risk reduction and positive living action plans. Particular groups are targeted, such as men at taverns or taxi ranks, adolescents at high schools, MSM and commercial sex workers.

In order to improve service provision, Bekker (2008) suggests risk stratification and retesting. She also emphasises quality training of young people as counsellors or risk reduction experts, who are able to discern whether a person should come back in three months, six months or a year, based on their level of risk. For example, people in a monogamous relationship who have both been tested and are both negative could be told to return for testing within one year; a person with a number of partners a week, who is not particularly concerned about condoms, might be advised to return in two months.

Bekker (2008) criticises inadequate training of VCT pre- and post-test counsellors, consisting of a mere ten-day course and then little checking on quality or skills, with the reality of a huge burden of telling someone that they are HIV-positive. She believes risk-reduction counselling is not being done well at all. What is needed is a more intensive programme of counselling, with risk-reduction experts or specialists asking the important, intimate questions about risk, and trying to keep people HIV-negative.

The DTHF will be evaluating the *Tutu Tester* and its suitability for replication in other communities and contexts. The financial cost of such a service would have to be reviewed when considering whether it could be replicated elsewhere. Bekker (2008) acknowledges SA cannot test everyone every month, as such resources are not available.

### ***VCT drives***

I have observed VCT drives during my tenure of employment at UCT in a unit tasked with providing an institutional response to the HIV epidemic. As distinct from permanent VCT sites, they last a day or more at a temporary location within a workplace or other setting. UCT utilises a central venue on its main campus. This testing approach results in far greater numbers being tested than at VCT permanent sites, as the testing process is made convenient.

Take for example, Student Wellness Service (SWS) at UCT in SA, which provides VCT at a permanent site and at VCT drives on campus. Provision of testing enables the institution to identify PLWHA and afford them the appropriate provision in terms of support and care.

The SWS records attendance at its various facilities. The difference in attendance between VCT site provision and drives is stark. With VCT by appointment, 1,166 students tested in year 2005 and 985 students in 2006. However, when VCT drives were initiated by SWS on the Upper Campus of UCT, over *two days* in September 2006, 1,052 people tested (637 females and 415 males). In March 2007, over five days, 2,472 students and 58 staff tested. Of these, 1,462 people had tested previously. In August 2007, over three days, 1,329 students and 46 staff tested for HIV. When the drive was taken to the Medical Campus over five days in August 2007, 496 students and 34 staff tested.

Of 1,003 respondents questioned on the VCT drives, 95 percent saw the benefit of HIV testing on the upper campus, and 93 percent saw the benefit of testing on all campuses. Seventy-eight percent preferred a drop-in system to an appointment system. When asked if and where they had tested before, the response was 61 percent on upper campus and only 38.9 percent at the permanent site.

Further feedback suggested that students and staff came to the drive because it was “convenient”, “accessible” and “quick”, people could go for counselling as a group, and it was “professionally conducted”. Service users appreciated the flexibility of being able to leave the venue after testing and then being able to return at their convenience for their results. Interestingly, few academic staff utilised the facility, perhaps as it did not afford them the privacy they preferred (a distancing from the student populace), or because they did not consider the facility to be convenient. Also, results were mostly HIV-negative, suggesting those who went for testing were not the most at risk.

### ***Resources and skills infrastructure***

The problem of resource constraints was tackled in interview. The literature largely applauds Botswana’s success in treatment provision, despite resource constraints. Yet in a much larger SA there are constraints of skills and infrastructure that militate against an effective response, particularly among rural populations (Butler, 2009). Maartens (2007) describes serious problems with provincial management at all sorts of levels in many provinces in this country,

although he singles out Gauteng and Western Cape as more efficient. He asserts that for such provinces, with poor management, infrastructure and staff capacity, it is difficult to implement something like opt-out testing. He believes that different strategies should be adopted in different provinces, as demands dictate.

Grimwood (2007) cautions against the segregation of functions that occurs in VCT testing. First, a counsellor talks to the client and then a nurse has to be located in order to perform the test, who might be in a different part of the building – the wait could take hours and people may leave without testing or receiving their results. Rather, he asserts, the process needs to be quick and efficient. Counsellors should be allowed to do the test, with the appropriate monitoring and regulation. For this to happen, training and capacity building is required, as well as the provision of reliable testing kits, approved by the Medicines Control Council (MCC). However, as counsellors are a weak lobby group, such a change would require a supportive call from already over-stretched professional clinical staff. Cameron (2007) also suggests suitably trained lay counsellors could undertake the functions presently being performed by both nurses and counsellors.

An additional difficulty, brought about partly by a lack of resources, is the lack of private spaces that would put the client more at ease. Bekker (2008) describes oversubscribed, busy clinics, where clients have to arrive early in the day and then wait for hours. She also explains that if adolescents encounter a bad experience of prejudice, they will not return to be tested.

So, are resources available for expansion efforts? Cleary (2008) describes VCT as an expensive means with which to test people; there are costs of counsellors and nurses and a space in which the service needs to be accommodated. Rooms also stand empty for much of the time, especially when the service is utilised by low volumes of persons. Cameron (2007) argues that as resources are scarce, it is not economically viable to continue in this way with pre-counselling, particularly as there is already a significant degree of knowledge.

When questioned on the availability of resources in SA for RHT, Cleary (2008) states that there are massive amounts of funds in the country (from PEPFAR, etc) that are not being spent. Money could be made available, but more healthcare workers would need to be trained and employed and healthcare facilities would need to be upgraded. Resources must not be taken from other services, as they would fail and a new service would become more of a

burden. Cleary suggests RHT might be cheaper per unit, but scale-up would naturally cost more. Bekker (2008) adds that funding should not be an issue, as testing is necessary in order for us to get on top of this epidemic, “in the same way that everybody gets a BCG vaccination”.

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## CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

### *Conclusion*

Testing for HIV is a vital component of a complete secondary prevention and treatment response to the epidemic in SA. Particularly as ARVs are increasingly available, early testing allows for those previously ignorant of their status to benefit from an early diagnosis, in order for the correct response to be instituted in terms of personal behaviour, appropriate care and the provision of treatment. It is also a cost-effective response, if illness and hospitalisation can be avoided.

There is concern, however, among clinicians, health practitioners and other commentators that the key testing approach of VCT is not working in SA. As numbers testing are low, insufficient persons are identified as being HIV-positive before they become ill with OIs and have to be hospitalised. Venter (HIV & AIDS Treatment in Practice, 2007) pulls no punches when articulating his frustration: “I hope there’s a middle road. But all I’m hearing is, let’s do more. Einstein said the definition of insanity is when you do the same thing over and over again and expect a different result”.

Glick (2005) points to the limitations of VCT evaluations to date, such as reliance on self-reports of behaviour, short follow-up periods, narrow outcome measures, the effect of treatment, aspects of the counselling process and unrepresentative study groups. Arguing that evaluations have failed to concern themselves with outcomes or effectiveness, Glick (2005) suggests “existing evaluations of VCT efficacy do not indicate either potential uptake of VCT or how behavioural responses to the programme might change as coverage extends”.... “as such, the implications for expanding the coverage of the program to a broader share of the target population are not clear”. HIV & AIDS Treatment in Practice (2007) suggests RHT and VCT should be compared, as “at present there is little to no comparative data to guide policy”.

Some commentators do not see VCT in itself to have failed, rather blaming inadequate implementation. Sedio (Kaisernetwork.org, 2006) questions why the government could not have instead increased VCT across the country in tandem with support structures of quality counselling and testing provided by civil society organisations. Creek et al. (2007) acknowledge that more people were coming forward for VCT in Botswana, prior to the

introduction of RHT, once the government committed to ARV rollout and increased public education around HIV. Human Rights Watch (2007) argues if opt-in testing is encouraged through more aggressive marketing, promotion by healthcare providers and ensuring access to ARVs, uptake would improve. HIV & AIDS Treatment in Practice (2007) acknowledges governments and funders need to make successful VCT programmes “more accessible and to increase public awareness of the need (and personal responsibility) to come in for testing”.

A number of commentators argue for a move from the polarised VCT versus RHT debate. Sofia Gruskin<sup>27</sup> (2005; 2006) asserts that “It’s time for the debate to be re-centred onto something that actually moves us forward towards sound public health and human rights practices, and away from framing these as divergent and even antagonistic concepts”. Mark Heywood (2006) states that “human rights and public health should not be at odds”. He argues it is a governmental duty to improve the capacity of the health service, enabling RHT whilst also observing human rights, improving access to facilities, and reducing the stigma and fear of knowing one’s status. Van Rooyen (2007) indicates that current strategies must be reviewed and urges us to move beyond debate and “artificial polarisation”, as insufficient people know their status and the testing response needs to be expanded to include client *and* provider-initiated models.

The preamble to the third SA AIDS Conference Declaration document (2007) states, “The polarisation between client-initiated and provider-initiated counselling and testing is not helpful and may hamper the achievement of objectives of the NSP”. Affirming its commitment to the NSP, which “provides a plan for... expanding access to HIV... treatment”, with HIV testing strategies, it speaks of the need for “dramatic expansion in the accessibility, availability and utilisation of counselling and testing services”. The NSP focuses on making VCT available and accessible (“for vulnerable groups”), training more personnel, expanding the services and “integrating them into community-based, non-medical and outreach service settings that are appropriately linked to ongoing prevention, treatment and care services”. Point (b) in the document speaks of “aligning the revised national policy on HIV counselling and testing with the NSP and WHO guidelines”.

So, there is clearly a consensus regarding the need to “drastically” expand HIV testing (Richter, 2006) and commentators propose a combination of interventions. Glick (2005) proposes a number of study arms in order to evaluate “different modes of service delivery”,



and the cost, in terms of finances and personnel, of each: comparing, for example, in-home counselling services, mobile testing, community-based services, standard healthcare setting services, RHT and mandatory testing. Such an evaluation would usefully assess the cost-effectiveness of each service delivery model.

Richter (2006) proposes that “other models” - such as opt-out testing - should complement and not replace VCT, which still has an important place, particularly in innovative forms, such as mobile clinics and testing incentives. Stegling (2004) also asserts that it is possible to look at VCT and other models of VCT, whilst pursuing a routine offer, where the client can refuse and make their needs known. Cameron (2007) also suggests that VCT should remain, despite its failings, with RHT being introduced in a parallel process in other settings.

UNAIDS (2006) also acknowledges the important contribution made by VCT, which has been in existence since 1985, but argue “a more diverse range of approaches is needed to increase knowledge of HIV status”... to include VCT (client-initiated) and a provider-initiated approach. De Cock (2006) and WHO/UNAIDS (2007) emphasise diversity – a place for both client- and provider-initiated testing.

According to Creek et al. (2007), “...the Botswana data provide encouragement that successful paradigm shifts can be made even in programs that have long been bound to VCT methodologies”. RHT programmes have been favourably reviewed in Botswana and elsewhere and Wanyenze et al. (2008) assert that they should be “an integral component of any expansion in HIV prevention, care and treatment services in Africa and other areas where the prevalence of HIV is high”. However, Denison et al (2008) indicate that the new and rapidly expanding approach of provider-initiated testing and counselling has not yet been comprehensively evaluated, and that there is a need for the same, particularly regarding its impact on behavioural outcomes. Where it is already utilised in SA healthcare settings, with pregnant women, TB patients and increasingly persons with STIs, its cost-effectiveness must be investigated in the context of an overburdened healthcare system, where resources would have to be reallocated, staff trained and a population sensitised.

Other approaches also need to be further researched in order for us to understand their efficacy. This would include the mandatory approach that would be difficult to implement in SA, as personal freedoms are constitutionally guaranteed. Home testing has also been

insufficiently researched at this time, but could be a viable option in rural districts in particular. There would have to be effective support structures in place to manage the (true or false) HIV test results, in order to mitigate against the risk of depression and even suicide. Testing at home by lay healthworkers and also home self testing (like pregnancy testing) merit further research.

VCT drives generally provide easy accessibility to the testing site, which tends to increase uptake. The mobile testing approach, like that tried by the DTHF in SA with a personal risk assessment, is an effective method to reach communities and can target particular groups perceived to be high risk. Immediate CD4 cell count measurement allows immediate access to the appropriate medical care. However, this is a high-cost measure that would have to be fully evaluated to measure whether it is replicable. Additionally, a lot can also be learned from the efforts of the business sector, and private-public partnerships, of bringing wellness drives to SA workplaces. It brings a handful of tests to the client, and its convenience, coupled with normalisation of the HIV test, has made it an effective testing method.

A need to scale-up is agreed, but should testing be targeted? High-risk groups, particularly pregnant women, persons with TB and STIs (generally tested when they seek healthcare provision), and also sub-groups such as truck drivers and MSM, are singled out for special attention by a number of commentators. Marks et al. (2005) suggest a combination of targeted HIV testing campaigns (for MSM) and broad-based screening campaigns will be needed to increase people's knowledge of their HIV serostatus. Van Rooyen (2007) also articulates the need for a variety of testing models that address context and specific target groups, and emphasise the voluntary, informed and confidential aspects. Acknowledging that HIV and AIDS is a human rights issue, she indicates that we must "create a social environment that encourages many more people to test voluntarily for HIV and, when necessary, to seek and receive medical treatment and social support".

The TAC (2009) argues that there is a need for a government campaign to promote testing for pregnant mothers, and that the government should "also plan scale-up strategies for testing and treatment of children and their fathers". Gruskin et al. (2008) state there has been insufficient documentation of strategies that are working towards achieving a scale-up of testing for pregnant women. Kass (2000) concludes that the decline in the rate of HIV perinatal transmission is due to the considered implementation of VCT, but that RHT would

serve to assist the targeting of all pregnant women who have wanted to test but have not been offered one, and that a new approach “reflects a commitment to the poor and minority women who have been targeted inappropriately”.

Bartlett (Bartlett & Mayer, 2006) suggests those at high risk should test more than once annually, and frequently retest. Bekker (2008) agrees with this risk stratification approach that is a component of the integrated DTHF mobile testing response. Mobile testing facilities are also useful for truck drivers, despite the difficulty of follow up care provision (Alcorn & Smart, 2006) and for women wanting to test without their partners knowing (Morin et al., 2006). Door-to-door testing has also been found to have high rates of testing acceptance (Alcorn & Smart, 2006).

Men in particular, and those who consider themselves to be at low risk, do not test for HIV. Recognising this, the NSP addresses “implementing a variety of models to increase counselling and testing uptake, with particular emphasis on the youth and men, and non-reproductive health service users” (p4, point (f)).

Médecins Sans Frontières (2006) recognises people only test once they are sick, as a motivation is needed to go for a test. The positives of testing should therefore be emphasized. Confidentiality must be guaranteed and private practitioners should be utilized. They suggest a few places where testing could be encouraged; blood donation, marriage preparation, visas, insurance, childcare pay-points, mobile testing to schools, pre-circumcision testing, testing days, role models who test, the workplace and community events.

Effective implementation of any testing method is crucial to its success. With this in mind, a “minimum package” is suggested by Gruskin et al. (2008) to accompany RHT, including condom and treatment availability, laws and policies that encourage best practice and testing uptake, and an infrastructure that allows for appropriate prevention, treatment and care; acknowledgement is made of the challenge in providing essential training with RHT roll-out, when health services are already overstretched.

For any new approach to work, it is important to increase capacity through sufficient funding provision and training. Alcorn & Smart (2006) cite Management Sciences for Health’s (MSH) research in SA, which found that in order to have a successful integration of testing into PHC,

staff had to be mentored and coached on a monthly basis, and “champions” had to be identified to drive the process. Richter (2006) emphasises that “a new testing model should require a strong emphasis on (re)training of medical practitioners”. There is a lack of health workers to cope with the added pressures of RHT (Cheng, 2007), but Gruskin et al. (2008) suggest that staff who would previously have conducted VCT would now be available to provide ARVs to the increasing numbers of PLWHA.

Bassett et al. (2007) suggest that the team of dedicated counselling staff available for their study may not be available at many public health facilities in SA. In resource-limited settings, indicates HIV & AIDS Treatment in Practice (2007), counsellors frequently lack sufficient training or remuneration, and quality assurance is not guaranteed. The inadequate provision of training in SA is criticised by Venter (HIV & AIDS Treatment in Practice, 2007), who suggests the three-day training of counsellors, “seen as cheap labour”, is inadequate, as “now they must deal with people’s fertility issues and issues around stigma, which highly trained psychologists can’t deal with”. Heywood (2005) motivates for the training of community health workers as counsellors to ensure informed consent, and greater government leadership in the form of availability of health information on treatment literacy and HIV in general.

The need for a holistic approach cannot be overestimated, as testing alone will not drive down the epidemic. Cost-effective programmes must be improved, including mass-media education campaigns, efforts to make condoms more widely available, and interventions to change high-risk behaviours (Frieden et al., 2005). Consistent application of proven strategies is required, such as syringe exchange, widespread condom distribution, testing expansion, notification of partners and medicalisation of the response to the epidemic. These proven interventions could prevent many new infections.

Controlling epidemics is a fundamental responsibility of the government, acting in concert with physicians, patients and communities. There is a delicate balance between protecting the public and the individual right to privacy. For any approach to succeed there needs to be a demonstration of government leadership, by committing financial resources and training staff appropriately. Frailties of the healthcare system are a concern in any discussion about the reenergising of a testing response, in order for more people to be tested. A genuine commitment would be needed from leadership in terms of destigmatising HIV and allocating the appropriate resources to testing and treatment. With a more active and less confrontational

partnership developing between civil society and government, fresh initiatives and further strides look more likely than ever before, which will go a long way towards normalising a chronic, manageable condition and making people comfortable with knowing their status.

The exceptional nature of HIV has to end and offering testing to people in a variety of settings will help to achieve this goal, with screening viewed like other lifestyle diseases. Most importantly, there must be “synergy between medical ethics, clinical, public health and human rights objectives” (WHO, 2007). There is no room for prolonged and polarised debates involving human rights and the public good, or for complacency, as we learn honestly from our failures and give room to expansion of HIV testing, with a comprehensive response that includes the routine or opt-out approach. A scale-up is clearly required of a more comprehensive package of testing for HIV, in recognition of the limitations to the VCT approach, together with a concerted effort to provide parallel prevention efforts (including education campaigns around concurrent relationships and male circumcision) and the appropriate treatment response, as more people learn their status and enter into care.

### ***Recommendations***

- Testing for HIV must be promoted as a necessary component of a secondary prevention response, together with efforts to destigmatise the virus and the testing process, which will serve to reduce gender-based discrimination and violence.
- If the argument presented in this thesis is correct, VCT is not the most effective means by which to test for HIV. Where this approach continues to be utilised, there is a need for re-training of personnel (allowing for task-shifting so that counsellors may perform both the test and counselling), the provision of safe spaces in which to test, and greater accessibility, for example by increasing VCT drives and mobile testing.
- The research has emphasised the urgent need to scale-up testing for HIV. For this to happen, ARV availability must be ensured and health infrastructure improved, without necessitating the reallocation of funds from elsewhere. Political will is necessary to ensure the funding of comprehensive testing and a rapid ARV roll-out.
- Efforts to normalise or de-exceptionalise the epidemic must be accelerated, complete with

legal safeguards. This would entail an injection of resources for appropriate training of health professionals (including counsellors to assume testing functions), which would help ensure persons are made aware of the importance of testing, symptoms are recognised, the right to decline is emphasised and appropriate follow-up support and treatment is provided.

- RHT should be utilised without extensive pre-test counselling, most particularly in the contexts of PMTCT, STIs and TB. For this to happen, healthcare facilities would have to be improved, and be more effectively utilised, ensuring privacy and safe and confidential spaces. The substitution of a special HIV testing facility with integration of the testing process into normal health practice (with fully integrated post-test counselling) would serve to counter stigma. A public awareness campaign would be necessitated explaining the focus on a new approach and how to access linkages to care, and this approach would require a comprehensive evaluation.
- Testing should also be made easier for healthy men, and married and older women whose perception of risk is low, who would be less likely to visit healthcare providers where RHT would be available (thus the necessity to combine approaches to testing). These groups might respond better to wellness screening or mobile testing.
- Mobile clinics should offer a range of health services, including (for example) screening for diabetes and obesity. This would help to normalise the service. Follow-up should be immediate if a person is HIV-positive, with the provision of a CD4 cell count if resources are available. Risk-stratification would encourage important re-testing. Additional costs may be offset against reduced hospital attendance. Before any method is to be replicated, there is need for more research into cost-effectiveness, public perceptions and efficacy.
- Other prevention strategies, such as public education concerning multiple and concurrent partners, also need to be scaled up in a way that is holistic and complementary to an effective HIV testing response.
- Effective implementation of any testing method is crucial to its success, and it should be incorporated into a 'package' of condom and treatment availability, laws and policies and an infrastructure that enables appropriate prevention, treatment and care.

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